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Integrated Palliative Care

a European Investigation into the Perspectives of Patients,
Family Caregivers and Healthcare Professionals



Marlieke den Herder - van der Eerden

Integrated Palliative Care

a European Investigation into the Perspectives of Patients,
Family Caregivers and Healthcare Professionals

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1

General introduction

Increasing number of patients with (advanced) chronic disease

Due to increased survival rates of cancer and other chronic diseases, people are now living longer with their disease¹. Moreover, increasing numbers of people have multiple chronic conditions² resulting in complex disease trajectories. Many patients with advanced cancer and/or chronic diseases suffer from symptoms such as pain (34-96%), breathlessness (10-95%), and fatigue (32-90%)³. Palliative care is an essential and effective approach for maintaining or improving seriously ill patients' quality of life until death occurs⁴⁻⁶. It has been estimated that within the next 20 years, the number of those in need of palliative care may increase by up to 47% in England and Wales⁷. Other countries with similar changes in demography and disease burden are likely to experience comparable rises⁷. These developments represent a great challenge for future healthcare provision in general, and specifically for palliative care provision in Europe⁷.

Palliative care

Palliative care aims to optimise the quality of life for patients with serious illness and their families through prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of multidimensional symptoms⁸. Palliative care encompasses a holistic vision and integrates the somatic, social, spiritual and psychological dimensions of care⁹. To address the multidimensional needs of patients and their families, palliative care often involves more than one medical and/or care discipline⁹⁻¹¹. These can be (palliative care) specialists, as well as general practitioners, nurses, physiotherapists, psychologists, social workers and spiritual caregivers⁹⁻¹¹. Therefore, in order to adequately support patients and their families, palliative care is based on interdisciplinary teamwork and requires continuous communication and collaboration between all healthcare professionals involved^{8, 10, 11}. Furthermore, patients are increasingly being recognised as a partner in the planning and management of their care process^{10, 11}. Studies investigating the effectiveness of palliative care provision for patients with advanced disease have shown promising results in terms of quality of life, quality of care and symptoms^{5, 6, 12-14}. Moreover, studies examining patients with advanced cancer have found that providing palliative care at an early stage may have a greater beneficial effect on quality of life and symptoms^{4, 5, 12, 15}. However, palliative care is a relatively young discipline¹⁶. Furthermore, due to a number of problems, palliative care in Europe is still sub-optimally organised and taught^{17, 18}.

Palliative care development in Europe

In the 1960s, palliative care started to develop thanks to Cicely Saunders and the opening of modern hospices in the United Kingdom¹⁶. Other European countries followed suit from 1977 onwards, with the foundation of palliative care services by enthusiastic pioneers in a variety of settings¹⁶. Influential bodies and governments increasingly began to recognise the need for palliative care, and in 2003, the European council published a set of

European guidelines on palliative care as being an essential and basic service for the whole population¹⁶. In the same year, the European Society for Medical Oncology (ESMO) published an editorial with policy statements on the integration of palliative care into standard oncology practice^{16, 19}. In 2002 the World Health Organisation first published their definition of Palliative care⁸. This was followed by a document on Better Palliative Care for Older People in 2004, that aimed at incorporating palliative care for serious chronic progressive illness within ageing policies, and promoting better care towards the end of life^{16, 20}. More recently in 2014, the World Health Assembly approved the first resolution on palliative care, calling upon countries globally to integrate palliative care into national health services²¹. Thanks to this, in recent years, a number of European countries have implemented national legislation or strategies to promote palliative care provision²². Furthermore, some countries now recognise palliative care as a separate medical discipline or specialty, while other countries consider palliative care as part of general care that is supported by palliative care experts only in very complex situations²³.

Problems with palliative care provision in Europe

Despite the increasing recognition of palliative care provision as a priority of European governmental policies and as a discipline, there are a number of problems. First, European countries differ in the extent to which specialised palliative care services have been developed¹⁷. The availability of these services is often insufficient to meet the needs of all patients in need of palliative care^{17, 24}. Second, many patients receive palliative care at a very late stage of their disease, or are even not referred or supported at all²⁵. To date, palliative care is still often related to terminal illness^{26, 27} and terminal care, while there is a lack of coordination of referrals between medical disciplines²⁸. Third, there is a lack of knowledge about the benefits of palliative care^{26, 29} and about prognostication³⁰. Fourth, palliative care often focuses on oncology¹⁶, but patients with other non-malignant diseases including Chronic Heart Failure (CHF) or Chronic Obstructive Pulmonary Disease (COPD) also have palliative care needs^{31, 32}. Despite growing attention for the palliative care needs of these patients with non-malignant diseases, they receive palliative care support less often than those patients with cancer^{25, 33, 34}. Fifth, the different services that provide palliative care are not integrated^{18, 29} which is apparent from the patient perspective. Many patients report a lack of information provision and a lack of information transfer between healthcare professionals³⁵. Additionally, many patients experience uncertainty during the transition from curative to palliative care due to poor coordination between healthcare professionals³⁵. Furthermore, patients often lack the knowledge and/or receive little guidance about the services available to manage their issues³⁶. These problems, combined with the growing palliative care population, urgently call for an integrated provision of palliative care.

Integrated care

In the past decades, an integrated care paradigm in healthcare has emerged as an answer to the problems of fragmentation, insufficient access, suboptimal quality of care and increasing healthcare expenditures for chronically ill patients^{2, 37, 38}. Integrated care is defined in Box 1. It involves a holistic vision and aims to improve quality of care for individual patients, service users and carers by ensuring that palliative care services are well coordinated around their needs^{37, 39}.

Box 1 Definition of integrated care

"Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors.

The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings.

The result of such multi-pronged efforts to promote integration for the benefit of these special patient groups is called 'integrated care'³⁷.

Micro, meso and macro level integration

Integration can take place at three different levels of care: micro, meso and macro levels⁴⁰ (Figure 1). Micro level integration focuses on the individual patient; it aims to achieve a coordinated care process around the patient's needs^{40, 41}. Components of micro level integration include shared guidelines, integrated care pathways, interdisciplinary teamwork, case management, shared decision making, and self management^{40, 41}. Meso level integration focuses on the organisation and services provided; it aims to reduce organisational compartmentalisation and promote collaboration and interdisciplinarity between the staff providing the service⁴¹. Components of meso level integration include relationships between organisations such as contracts, strategic alliances, or knowledge networks, as well as professional relationships e.g. interdisciplinary teamwork, shared roles and responsibilities^{40, 41}. Macro level integration focuses on the healthcare system with the aim of coordinating and aligning national and regional finance schemes, policies and regulations that promote integration of fragmented (health)care services^{40, 41}.

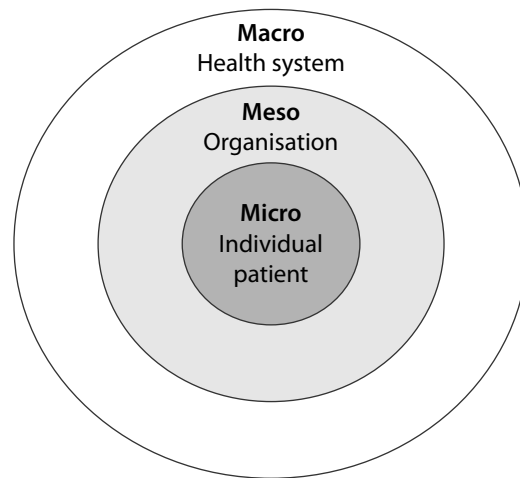


Figure 1 Integration at the micro, meso and macro level

Patient participation and shared decision making

Currently, involving the patient is increasingly considered a prerequisite for achieving a coordinated care process around the patient's needs, i.e. integrated care^{38, 42}. In this context, the main concepts mentioned are patient participation and shared decision making⁴³. Patient participation means that decisions about the content, planning and organisation of the patient's care trajectory are based on a dialogue between the patient and the healthcare professional(s)^{43, 44}. Shared decision making specifically means that both the healthcare professionals and patient exchange information and jointly deliberate on an agreed treatment decision⁴⁵. Both concepts acknowledge patients' autonomy as well as their values and wishes, and recognise the knowledge and expertise of both the healthcare professionals and the patient^{43, 46, 47}. Although participation and shared decision making are often used interchangeably⁴⁸, participation has the broader meaning of involving patients in every step of the care trajectory, not just making decisions about medical treatment⁴³. While most studies on patient participation focus on the patient-physician-dyad⁴⁹, palliative care also needs to account for the important role of family caregivers in the content, planning and organisation of the patient's care trajectory^{10, 11}.

Integrated care research

Studies examining the effectiveness of integrated care programs have shown mixed results⁵⁰⁻⁵². Several (meta-)reviews have found positive outcomes of integrated care programs in terms of e.g. patient satisfaction⁵³, quality of care, quality of life, hospital use^{38, 50, 51, 54, 55} costs⁵⁶, coordination, continuity of care⁵⁷⁻⁵⁹ and adherence to treatment

guidelines⁵⁵. In many reviews on integrated care, a majority of studies focus on the Chronic Care Model. This is one of the best known models and is a forerunner of integrated care models as it provides a comprehensive framework for the organisation of healthcare services in order to improve outcomes for patients suffering from chronic diseases^{60, 61}. The Chronic Care Model includes six components: mobilising community resources, promoting high quality care, enabling patient self-management, implementing care consistent with evidence and patient preferences, effectively using patient or population data, cultural competence, care coordination, and health promotion⁶². Programs that focus on multiple components of the Chronic Care Model have been shown to be especially effective^{50, 51}. In a recent review of reviews⁶³, the authors found that most common elements of integrated care models include multidisciplinary teams, comprehensive assessment, and case management. However, the optimal model of integrated care needed depends on the particular setting and care goals^{64, 65}.

Integrated palliative care

Palliative care relates to integrated care in several ways: it has a holistic, patient-centred vision, requires interdisciplinary teamwork, and an early application alongside other treatments⁸. Hence, integrated care may be a useful paradigm for evaluating current palliative care practice in Europe, and for investigating how its integration can be improved^{66, 67}. Integrated palliative care refers to the integration of a palliative care approach into the micro, meso and macro levels of (health)care to ensure that all patients with palliative care needs receive adequate palliative care, where and when they need it^{68, 69}. However, an overarching definition has yet to be agreed. Moreover, although research efforts on initiatives for practising integrated palliative care are currently receiving increasing attention, in 2013 InSup-C (Box 2) was one of the few^{70, 71} studies that focused on integrated palliative care as a research subject. Therefore, there is no blueprint for organising and providing integrated palliative care that can be used for evaluating how best to improve the integration of current palliative care practice in Europe.

The value of qualitative research for integrated palliative care

Integrated palliative care practices can be considered complex healthcare interventions⁷³. To understand the working mechanisms and outcomes of complex healthcare interventions, the use of mere quantitative methods may not provide valuable results. Findings of studies about complex healthcare interventions are often difficult to interpret, since the components and mechanisms constituting the intervention are often not well described, not known, or not understood^{74, 75}. Increasingly, mixed-methods designs are proposed for evaluating complex healthcare interventions. In these designs, qualitative research methods complement quantitative research methods⁷³. Qualitative methods aim to provide an understanding of social phenomena such as human interaction (e.g. why and how healthcare professionals collaborate) and patient behaviour (why patients do or do

Box 2 InSup-C

InSup-C (“Integrated Supportive Care”) ran between 2013 and 2016 with the aim of identifying prerequisites for integrated palliative care in Europe, with the overall objective of improving service provision and service user outcomes.

The main activity within the InSup-C project was a prospective multiple embedded case study⁷² about the experiences of patients with advanced Cancer, COPD and Chronic Heart Failure, their family caregivers and healthcare professionals, with care provided in several promising integrated palliative care initiatives in five European countries. The five countries included Belgium, Germany, Hungary, the Netherlands and the United Kingdom. The study used a mixed-method approach including individual and group interviews, as well as a number of questionnaires.

InSup-C was funded by the European Union Seventh Framework Programme (FP7/2007-2013/HEALTH, under grant agreement 305555). InSup-C was coordinated by Dr Jeroen Hasselaar of Radboud University Medical Center, Nijmegen, the Netherlands. Other partners were: University Hospital, Bonn, Germany; International Observatory on End-of-Life Care, Lancaster University, Lancaster and Sheffield University, United Kingdom; University of Pecs Medical School, Pécs, Hungary; University Hospital Leuven, Leuven, Belgium; World Health Organization, Geneva, Switzerland; European Association for Palliative Care (EAPC OnLus), Milan, Italy; Erasmus University, Rotterdam, the Netherlands; University of Navarra, Navarra, Spain; and Mount Sinai Medical Center, New York, USA.

not comply with treatment)⁷⁶. Qualitative methods can generate an understanding of whether and how a model works, why particular answers were given in surveys, and can inform the design of subsequent studies^{73, 75-77}. In case of complex behaviours, attitudes and interactions, e.g. during changes in healthcare organisation, qualitative methods can provide insights that quantitative methods alone cannot⁷⁶. Therefore, qualitative research is pre-eminently appropriate in an unexplored research field like integrated palliative care⁷⁸. It can generate an understanding of how integrated palliative care currently takes place, and provide insights into themes and categories that are important in this context⁷⁹.

Multiple embedded case study design

In an embedded case study design, a case is examined at several levels in order to collect in-depth information⁸⁰. Exploring the case’s embedded subunits generates more insights into the case itself⁸⁰. A multiple embedded case study design involves a number of cases and also enables cross-case comparison. (Multiple) embedded case study designs often use mixed-methods research, including individual and group interviews in addition to questionnaires⁸⁰. A multiple embedded case study is considered an appropriate design

for an in-depth investigation of the current implementation of integrated palliative care in a range of palliative care initiatives, as it includes the experiences of healthcare professionals, patients, and family caregivers in daily care giving practice. In this European study, the cases are palliative care initiatives from different European countries, and the embedded subunits are patients, family caregivers, and professional caregivers, who all share their experiences with care provision within the initiatives.

Aim of the thesis

This thesis aims to examine how integrated care is currently implemented in the clinical practice of preselected palliative care initiatives in several European countries. The following research questions were formulated:

- 1) How can an international study on current integrated palliative care implementation be designed including an agreed work definition of integrated palliative care?**
- 2) How do patients and family caregivers perceive integrated palliative care?**
 - 2a) What is the composition and quality of care networks of patients receiving palliative care from several integrated palliative care initiatives in five European countries and how do these patients perceive the integration between healthcare professionals within their care network?
 - 2b) How do patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in five European countries perceive continuity of care?
 - 2c) How is the participation of patients and family caregivers shaped in palliative care trajectories in the Netherlands?
- 3) How is integrated palliative care currently implemented from the perspectives of healthcare professionals?**
 - 3a) What are core elements, facilitators and barriers of integrated palliative care implementation in seven European countries from the perspectives of leaders in the field of palliative care?
 - 3b) How is integrated care currently developed within several integrated palliative care initiatives in five European countries as perceived by the healthcare professionals involved in these initiatives?

Outline of the thesis

The content of this thesis is largely based on the European InSup-C project and predominantly focuses on the overall international findings.

Chapter 2 describes the protocol for the prospective multiple embedded case study conducted in the InSup-C project. It describes the procedure for selecting three to five integrated palliative care initiatives in Belgium, Germany, Hungary, the Netherlands and the United Kingdom. It describes a mixed-methods approach including individual and group interviews as well as questionnaires. Furthermore, the data analysis procedures for both the interviews and questionnaires are described. This chapter answers research question 1.

Chapter 3 investigates the composition of care networks of patients receiving palliative care, and how integration between healthcare professionals involved in these networks is perceived by patients with advanced Cancer, COPD and CHF in Belgium, Germany, Hungary, the Netherlands and the United Kingdom. Furthermore, it investigates whether perceived integration is associated with overall satisfaction. This study used a cross-sectional explorative design. This chapter answers research question 2a.

Chapter 4 examines how continuity of care is perceived by patients with advanced Cancer, COPD or CHF and their family caregivers receiving care from integrated palliative care initiatives in Belgium, Germany, Hungary, the Netherlands and the United Kingdom. The study used a longitudinal qualitative design including two semi-structured interviews for each respondent. This chapter answers research question 2b.

Chapter 5 describes how participation is shaped in palliative care trajectories from the perspectives of patients and their family caregivers receiving care from several integrated palliative care initiatives in the Netherlands. The study used a qualitative secondary design. This chapter answers research question 2c.

Chapter 6 presents the results of a study in a preparatory phase of the multiple embedded case study conducted in the InSup-C project. It involves a qualitative study examining the opinions of leaders in palliative care in seven European countries about core elements, facilitators and barriers of integrated palliative care implementation and recommendations for future policy and practice. This chapter answers research question 3a.

Chapter 7 examines how integrated palliative care takes shape in practice across four key domains of integrated care (content of care, patient flow, information logistics, availability of (human) resources and material) from the perspectives of healthcare professionals involved in several integrated palliative care initiatives in Belgium, Germany, Hungary, the Netherlands, and the United Kingdom. The study used a qualitative group interview design. This chapter answers research question 3b.

Chapter 8 presents and discusses the main findings of this thesis in light of relevant and recent literature. Moreover, this chapter includes a number of recommendations for clinical practice, research, policy and education.

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2

Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe

Protocol for an international, multicenter, prospective, mixed method study

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Abstract

Background

The number of people living with advanced cancer and chronic disease has increased worldwide. Many of these patients could benefit from palliative care, focusing on optimising the quality of life of patients and their families facing problems resulting from life-threatening diseases. However, fragmentation and discontinuity of palliative care services often result in suboptimal palliative care. In order to overcome these problems, models using an integrated care approach are increasingly advocated in palliative care services. Although several models and definitions of Integrated Palliative Care (IPC) have been developed, the effects of integrated care are still under-investigated. Knowledge of the key components that constitute successful palliative care integration is still lacking. This mixed methods study will examine the experiences of patients, family caregivers and professional caregivers in order to provide insight into the mechanisms that constitute successful palliative care integration.

Methods/Design

Prospective multiple embedded case study. Three to five integrated palliative care initiatives will be selected in Belgium, Germany, Hungary, The Netherlands and the United Kingdom. Data collection will involve Social Network Analysis (SNA), a patient diary, semi-structured interviews, and questionnaires: Palliative care Outcome Scale (POS), Canhelp Lite, Caregiver Reaction Assessment (CRA). Patients and family caregivers will be followed in 4 consecutive contact moments over 3 months. The diary will be kept weekly by patients. One focus group per initiative will be conducted with professional caregivers. Interviews and focus groups will be tape recorded, transcribed and qualitatively analysed using NVivo 10. SPSS Statistics 20 will be used for statistical analysis.

Discussion

This study will provide valuable knowledge about barriers, opportunities and good practices in palliative care integration in the selected initiatives across countries. This knowledge can be used in the benchmark of integrated palliative care initiatives across Europe. It will add to the scientific evidence for IPC services internationally and will contribute to improvements in the quality of care and the quality of living and dying of severely ill patients and their relatives in Europe.

Background

The number of people living with advanced cancer and chronic non-malignant disease has increased worldwide¹. Patients often suffer from symptoms related to their illness and experience reduced quality of life^{2,3}. Many of these patients could benefit from palliative care, focusing on optimising the quality of life of patients and their families facing problems resulting from life-threatening diseases⁴. Literature has shown that palliative care has a positive impact on the quality of life of patients with advanced cancer and advanced chronic disease at lower costs^{5,6}. However, fragmentation and discontinuity of palliative care services in Europe often result in suboptimal palliative care⁷. Many patients receive palliative care in a very late stage of their illness or not at all. This applies even more to patients with non-malignant disease, such as patients with Chronic Obstructive Pulmonary Disease (COPD) and Chronic Heart Failure (CHF), compared to patients with malignant disease⁸⁻¹⁰. As a result, many patients lack adequate control or relief of symptoms to maintain quality of life. Moreover, these patients often visit out-of-hours services due to uncontrolled pain and other symptoms, or experience hospital admissions during the last phase of life^{11,12}. Consequently many patients are not able to die at their preferred place of death^{3,13}.

In order to overcome these problems, models using an integrated care approach are increasingly advocated in palliative care. These endeavours focus on the integration of palliative care either early in a certain disease trajectory and/or in the organisation of care, by collaboration and consultation with experienced (palliative) care services and specialists^{14,15}. Initiatives using an integrated palliative care (IPC) approach have shown promising results, reducing fragmentation and enhancing continuity of palliative care¹⁴. Greer⁵ and Zimmermann¹⁶ showed that integration of palliative care into standard care for patients with malignant disease, could positively affect outcomes such as quality of life, quality of care and symptoms. Epiphaniou¹⁷ showed that integration of palliative care into the organisation of care, by means of improved coordination and communication between all primary and secondary caregivers involved in the palliative care network of patients with lung cancer and COPD, enhanced continuity of care. Although several models and definitions of IPC have been developed, the effects of integrated care are still under-investigated^{18,19}. Promising results are mainly based on the evaluation of individual services, using retrospective or cross-sectional data^{8,20,21}. Knowledge of the key components that constitute successful palliative care integration is still lacking^{22,23}.

In order to address this knowledge gap, the EU-funded (FP7) collaborative research project “Patient-centred integrated palliative care pathways in advanced cancer and chronic disease” (InSup-C) was planned. The aim of the overarching study is to identify best or promising practices in IPC across Europe. A central component of the project is a prospective mixed methods cohort study that will be carried out with patients and their caregivers receiving palliative care. This mixed methods study will examine the experiences of patients, family

caregivers and professional caregivers with palliative care provision and will provide insight into the mechanisms that constitute successful palliative care integration. We expect that this knowledge will contribute to the improvement and implementation of IPC across Europe.

The research question addressed in this study is:

How do patients with advanced cancer, COPD and CHF, their family and professional caregivers experience care provision in a range of IPC initiatives in five European countries?

This question will be explored by an examination of what care is provided by whom and to what extent caregivers work together to provide patient-centred, continuous care. Important aspects of this exploration also entail whether the needs, problems and expectations of patients and family caregivers are met, and how relationships between patients/family caregivers and professional caregivers are experienced. As family caregivers are often closely involved in palliative care provision, their perspectives on caring for the patient will also be explored. Subsidiary questions emerging from the research question are:

1. How is the care network of the patient organised with respect to the type, properties and quality of relationships between patients and family/ professional caregivers?
2. What opinions do patients and family and professional caregivers have on the continuity and quality of care provided?
3. How do patients rate their symptoms and quality of life?
4. How do family caregivers rate their burden or reward of care giving?

The objective of this paper is to present the protocol of this patient and caregivers study, including a detailed description of the study design and the methodological approach. The methodology described in this paper will also serve as a reference for future publications about the study.

Methods/Design

Study design

This study uses a prospective multiple embedded case study design²⁴. This design enables us to examine the quality of care of a range of IPC initiatives in-depth and over time, as it is experienced in daily care giving practice. This design also allows us to explore the embedded subunits of multiple cases in order to understand more about the case itself. In this study the cases are IPC initiatives (see Figure 1). The embedded subunits are patients, family caregivers and professional caregivers and their experiences with care provision in the initiatives. Detailed analysis of these embedded subunits includes: the

organisation of the patient's care network and relationships with and collaboration between professional caregivers in this network, perceived quality of care, quality of life and symptoms of patients, perceived burden and reward of care giving of family caregivers. The multiple case study design also allows for comparison between IPC initiatives, each one with its own organisation and set-up (roles, responsibilities, relationships). In order to enable comparison the data collection methods for patients, family caregivers and professional caregivers will be the same for all IPC initiatives.

Selection of IPC initiatives (cases)

The study will be conducted in five European countries; Belgium (Flanders region), Germany, Hungary, The Netherlands and the United Kingdom. In each country, three (Belgium) or five (the other countries) IPC initiatives will be recruited to the study. It is a novelty that in palliative care research patients and (family) caregivers' views will be investigated at this large European scale. As integrated palliative care is an upcoming and under-investigated field, there is no theoretical framework or prevailing standard on which we can base the number and selection of cases (IPC initiatives). We expect that three-five initiatives per country and 23 in total will be enough to generate insight in how current IPC initiatives vary in service provision (e.g. diagnostic group(s), organisational structure, caregivers and settings that are involved, etc.) and what this means for patients' and caregivers' perspectives on the (quality of) service provision and its barriers and benefits. Although this number may not be enough to reach full saturation, we need to take into account the reality of inclusion of a rather vulnerable patient group which will demand large efforts in time and resources in the project team.

As there was no unanimously agreed definition of IPC beforehand, the project team formulated a working definition. This was based on the literature²⁵⁻²⁹ and on discussions in several project team meetings. The final definition is as follows: *"Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid"*. Using this definition and the criteria below, which derived from the definition, local initiatives in the five countries will be identified, examined, and selected for inclusion. Experts in palliative and integrated care across the participating nations will be consulted in the identification process.

Selection criteria for IPC initiatives

1. the initiative is an established local palliative care collaboration;
2. the collaboration must contain at least two different organisations;
3. a hospital can be part of that collaboration;
4. collaborating healthcare professionals must provide direct patient care (not only an advisory function);

- the collaboration has a multidisciplinary background (professionals of different professions must be involved, e.g. physician (specialist, GP), nurse (specialist), social worker, Allied Health Professional, spiritual worker, complementary therapist, others);
- the collaboration aims to provide palliative care for one or more target diagnostic groups in the study (COPD/CHF/Advanced cancer).

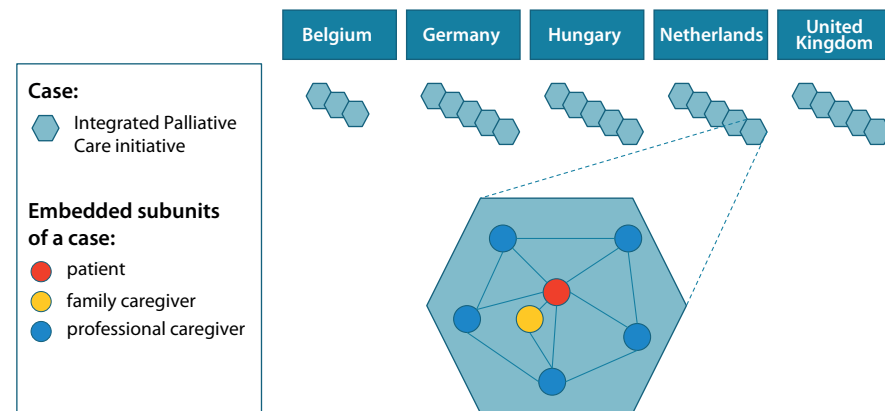


Figure 1 Multiple embedded case study design of our study about the experiences of patients, family and professional caregivers with IPC in Europe.

Participants (embedded subunits)

Patients with advanced cancer, COPD or CHF, their family caregivers and professional caregivers will be recruited from each IPC initiative taking part in the study. Signed informed consent forms will be obtained before study entry.

Patients and family caregivers

Patients (and if present one family caregiver per patient) will be recruited by their attending doctor or other professional involved in their care. A family caregiver, defined as the person who non-professionally takes care and supports the patient for most of the time, will be identified by the patient. Family caregivers may not necessarily be a family member³⁰. Participants need to meet the inclusion criteria (see "Inclusion criteria for patients and family caregivers") in order to be eligible to take part in the study. In order to gain variation in patients' experiences with care provision at different time points in their disease trajectories, we strive to purposively recruit patients who are at different time points in their disease trajectories.

Inclusion criteria for patients and family caregivers

Patients & family caregivers

- 18 years or above
- Able to communicate in the national language (Dutch, English, German, Hungarian)
- Cognitively able to complete questionnaires and to participate in interviews.

Patients

- The patient's attending doctor answers "No" to the surprise question: "Would you be surprised if the patient died within 1 year?"
- Any of the following diagnoses:
 - Advanced cancer (cancer with local progression and/or distant metastasis at presentation)
 - Severe heart failure in accordance with NYHA classification stage III-IV
 - COPD Gold stage IV classification

We aim to achieve a total sample of 138 included patients and 138 family caregivers. This means an inclusion of six patients and six family caregivers per IPC initiative. We expect that this small number is attainable within 18 months, as this will be done in a multicenter study across 5 European countries with dedicated researchers per site. Herewith, we have also taken into account that the qualitative data analysis is not postponed to the end of data collection, but will already start after the first interviews, as data analysis in qualitative research is an iterative process until the end of the data collection period. In the recruitment of patients and family caregivers we will take account of a 30% attrition rate³¹.

Professional caregivers

Professional caregivers who are involved in the patient's care network (identified by the patient) and who are involved in the selected IPC initiatives will be invited for participation in a focus group. We aim to conduct 23 focus groups each with 6-10 participants. In order to maximize an exploration of different perspectives on the initiative as it is experienced in practice, we aim at a convenience sample containing various professional roles and responsibilities within the initiative. The final invitation list will be made after inclusion of the last patient, with alternatives in case of decline.

Data collection

There will be four consecutive contact moments with patients and family caregivers with an interval of one month (baseline, month 1, month 2, month 3). These are displayed in Table 1. At baseline and at month 3 there will be a face-to-face contact with the patient and his/her family caregiver. During these contacts we will conduct semi-structured interviews and assess the caregiver network analysis with the patient. At baseline, month 1, month 2 and month 3 the patient and family caregiver will complete the questionnaires. Weekly, between baseline and month 3, the patient will keep a diary. The questionnaires

and diary will be completed by the patient and/or family caregiver themselves or with the help of a researcher, by telephone.

If a patient dies during the study period, we will contact the family caregiver to offer our condolences and, dependent on the circumstances of the bereaved carer, will ascertain if they wish to have a final semi-structured interview. If so, we will contact them again to make an arrangement for the final interview at a time of their convenience between 4 and 12 weeks afterwards. We will not administer any questionnaires anymore. Per initiative there will be one focus group with professional caregivers at the end of the data collection. The expected duration of the entire study period will be 18 months, including recruitment, data collection, and analysis. Data collection is scheduled to start in June 2014 and to finish at the end of 2015. The data collection methods that will be applied to assess the outcome parameters are described in Table 1.

Patients

Social Network Analysis

The organisation of the care network of patients, including the type, properties and quality of relationships between patients, family caregivers and professional caregivers will be examined using a social network approach. Social network analysis (SNA) is a method to investigate patterns of relations, communication and collaboration between actors in a given network. In health care research SNA has been applied to investigate organisational structures, processes, and service provision. The results can be used to design or implement interventions to change health care policy or practice³²⁻³⁴. To analyse the organisation of the patient's care network a structured questionnaire, based on previously published questionnaires^{35, 36}, was developed by the project team. The final questionnaire (see Appendix 1) contains 13 questions and examines contacts between patient and caregivers in his/her care network, evaluation of services provided, perceived continuity of care, and collaboration between caregivers in the network. The patient's care network, including the type, properties and quality of relationships will be further explored using a patient diary and semi-structured interviews (discussed below).

Patient diary

A patient diary will be used to collect data about the perceived quality of care during the palliative care trajectory and the nature of professional caregiver contact. The diary will be kept weekly and contains two questions:

1. Did you have contact with a non-family caregiver during the last week?
(e.g. palliative care team consult, home care, GP, psychologist, hospital, other)
2. If yes, how would you rate the care you received?

Table 1 Data collection schedule.

Outcome parameter	Data collection method	Baseline	Week 1-4	Month 1	Week 5-8	Month 2	Week 9-12	Month 3	End of data collection
Patient									
Organisation of patient's care network, Collaboration between professional caregivers	Caregiver network analysis questionnaire	×						×	
Experiences with IPC initiative, Quality of Care	Semi-structured interview	×						×	
Quality of Life, Perceived symptoms	Diary		×		×		×		
Satisfaction with Care	Palliative care Outcome Scale	×		×		×		×	
Family caregiver	Canhelp Lite	×		×		×		×	
Experiences with IPC initiative, Quality of Care	Semi-structured interview	×						×	
Quality of Life, Perceived symptoms of patient	Palliative care Outcome Scale	×		×		×		×	
Satisfaction with Care	Canhelp Lite	×		×		×		×	
Burden & Reward of care giving	Caregiver Reaction Assessment	×		×		×		×	
Professional caregiver									
Experiences with IPC initiative, Quality of Care, Collaboration between professional caregivers	Focus group								×

The answer to the second question is given on a 5-point (Likert) scale, rating from 1 (poor) to 5 (excellent). Information provided in the diary will be explored in the last semi-structured interview. If the patient is unable to fill in the diary on his/her own the family caregiver/researcher may assist the patient.

Recording contacts between patients and their caregivers will provide evidence about care utilisation and perceived quality. Information gleaned from the patient diary and the SNA will enable an in-depth examination of the development and changes in the patient's care network over time. Combining data from both tools – together with that from the semi-structured interviews (discussed below) – will also allow a detailed explication of the extent of palliative care integration in the participating initiatives.

Patients and family caregivers

Semi-structured interview

Semi-structured interviews will be used to explore views of patients and family caregivers about their experiences with the IPC services they receive. These will be conducted by trained researchers from the project teams in each of the five participating countries. In principle the interviews will be conducted separately. For practical reasons the researcher may deviate from this and conduct the interview with both patient and family caregiver at the same time. In order to minimize influences between patients and family caregivers when they are together, we will emphasize before the start of the interview that we are interested in both the personal view of the patient and the family caregiver. Further we will ask either the patient or family caregiver directly for his/her own view, e.g.: "Is this problem you just mentioned also a problem in your own view, or is this a problem in the view of [name of family caregiver]?". Patients in this study are vulnerable and often more comfortable in the surrounding of their partner, so we do not want to be too strict in a separate interview to restrict the burden for the patient as much as possible. Topics of the interviews include:

1. Exploration of problems and needs of the patient
2. Exploration of the contacts and relationships of patients and family caregivers with professional caregivers
3. Exploration of satisfaction and perceived deficits in service provision from the perspective of patients and family caregivers
4. Exploration of the views of patients and family caregivers on the collaboration between professional caregivers in the care network of the patient. A second interview at month 3 will enable an exploration of the care experience over time.
5. The final interview will include a review on the most important problems and needs in the dying phase from the perspective of the bereaved family caregiver, which caregivers were involved in this phase and just after bereavement, and how the care provision was experienced by the bereaved family caregiver.

Questionnaires

Demographic and other relevant data that describe the population contributing to this study will be collected at baseline using the questionnaires presented in Table 1. With regard to the vulnerable population of seriously ill patients and the international nature of the study, questionnaires were selected based on: validation and/or applicability in palliative care populations of patients with cancer and chronic disease, time needed for completion in order to limit burden of assessment, and available translations into the national languages of the countries involved in the study (Dutch, English, German, Hungarian). Questionnaires that had not yet been translated were translated using a forward-backward translation procedure³⁷.

Palliative care Outcome Scale (POS)

The Palliative care Outcome Scale – version 1 will be used with patients and family caregivers to measure quality of life and perceived symptoms of patients. It is widely used and tested and is validated for use in palliative care. The completion time is short, approximately 7 minutes³⁸. The POS has been translated into Chinese, English, Dutch, German, Italian, Portuguese, Punjabi, Spanish and Urdu. There is a patient and a caregiver version.

Canhelp Lite

The Canhelp Lite will be used with patients and family caregivers to measure satisfaction of care. It was developed in Canada, validated for use in palliative care and applied to patients with advanced, life-limiting illnesses. It is applicable in both institutional and community based settings. There is a Patient Questionnaire, Caregiver Questionnaire and a Bereavement Questionnaire³⁹. Only the Patient Questionnaire and Caregiver Questionnaire will be used in this study. The Canhelp Lite has a completion time of approximately 10 minutes for both the patient and caregiver version and has been translated into English and French.

Family caregivers

Caregiver Reaction Assessment (CRA)

The Caregiver Reaction Assessment will be used with family caregivers to measure their perceived burden and reward of care giving. It measures both positive and negative reactions to care giving⁴⁰. The CRA is widely used and extensively tested and has a completion time of approximately 10 minutes. It has been translated into Dutch, English, German, Japanese, Norwegian and Thai. The CRA has been applied to family caregivers as well as significant others for patients with physical, chronic and mental impairments and malignant diseases⁴¹.

Professional caregivers

Focus group

Focus groups will be used to obtain insight into the experiences of professional caregivers with providing IPC. The interviews will address professional caregivers' views concerning the quality of IPC in their initiative and issues involved in working across organisational boundaries to provide that care. One focus group will be conducted in each of the participating services. Topics that will be discussed include: components considered important for high quality integrated care, set-up of the initiative (roles, responsibilities, relationships), expectations and/or future improvements.

Data management and analysis

Anonymous participant data will be stored in a protected database Castor EDC (Electronic Data Collection) with a login function. The master database will be kept at the centre of the research coordinator Radboud University Medical Centre in the Netherlands.

Interviews will be tape recorded and transcribed verbatim. Transcriptions will be analysed using content analysis techniques supported by the qualitative analysis software package NVivo 10. Researchers from each partner country will jointly develop a preliminary coding schedule with the results of the first two interviews. This code book will be used for the baseline and final interviews. The codes and themes will form the basis of the coding strategy throughout data collection and the data analysis. Analysis will be iterative during the fieldwork phase in order to allow emergent themes to be incorporated into the data collection. This procedure will also be used to analyse the focus group data. For the focus groups a separate code book will be developed by the researchers.

In general, the analysis will focus on the similarities and differences between the IPC initiatives (e.g. the diagnostic group(s), organisational structure, the caregivers and settings that are involved in the care provision) and what these mean for the views of patients, family caregivers and professional caregivers on the care provision. The analysis will result in five country specific reports about the experience of using and providing IPC in the last year of life. IPC country specific reports will be analysed and summarised in one overarching document. This report will provide a trans-national perspective on the lived experience of IPC services from the particular standpoints of the service users and professional caregivers involved.

Statistical analysis will be performed using SPSS Statistics 20 on the quantitative data derived from the questionnaires. We will use descriptive statistics such as frequencies, crosstabs, means, standard deviation in the data analysis in order to describe the characteristics of the participant population. During this analytical phase we will integrate the quantitative variables and qualitative findings so as to draw a more complete picture of IPC across Europe.

Training sessions

In order to assure high quality and uniformity of data collection and analysis in all five countries two training sessions will be organised. These sessions will support researchers in preparing and conducting interviews, performing reliable and valid qualitative research and processing data. Training will also focus on preparing researchers to conduct research with potentially vulnerable participants.

Ethical issues

As in all ethically conducted research, informed consent will be obtained to guarantee voluntary participation and participants may withdraw at any time should they wish to. For these reasons we believe that the potential for risk in this study is minimal and that it may even benefit participating patients and family caregivers^{42, 43}.

In order to test this expectation we added four questions about how patients experienced participation in the interview study ("thoughts on the studies") and potential distress or satisfaction related to the study participation. These questions will be asked after the first and final patient interview. The questions were derived from Gysels⁴² who conducted a qualitative study with 76 palliative care patients from the UK. This study concluded that although patients experienced thinking about the future as difficult, sharing problems was therapeutic and being able to contribute to research was considered empowering⁴². Using the same questions in our study enables us to contribute to this ethical debate.

In order to minimize the burden of data collection on patients and family caregivers, questionnaires and diaries have a short completion time and the total duration of interviews will be limited to a maximum of 60 minutes. Interviews will be conducted by researchers who are experienced and well trained in research with vulnerable patients.

For professional caregivers, participating in the study may be beneficial because during the interviews they will have the opportunity to reflect on their experiences of the provision of palliative care and their collaboration with other professional caregivers involved in the IPC initiative under examination. This reflection could be a prompt to improve their collaboration with other caregivers and may provide an impetus to improve daily practice in their local collaborations.

Ethical approval has been granted by the ethical review committees of Hungary, The United Kingdom and Germany. The study does not fall within the remit of the Dutch Act on Human Research and for this reason did not have to go through the Dutch ethical review committee. In Belgium the ethical review procedure is in a final stage.

Discussion

Strengths

The prospective multiple embedded case study design allows for exploration of IPC trajectories as experienced by patients and family caregivers. This includes palliative care service utilisation, perceived quality of life, quality of care, symptoms and perspectives on the collaboration between caregivers in the patient's care network. The prospective design allows the possibility to examine these palliative care trajectories more in-depth. It also enables the exploration of IPC services utilisation and the collaboration between caregivers within the patient's care network throughout the palliative care trajectory over time.

The international perspective of this study has the advantage that we can compare experiences of service users and providers in a range of different health care contexts in Europe. We expect that this will provide valuable information about barriers, opportunities and good practices in palliative care integration in the selected initiatives across countries. This information can be used in the benchmarking of initiatives in Europe and the further implementation of integrated care.

Challenges

One challenge of a patient study on an international scale is that it needs to meet ethical requirements in several countries. Our study shows that it is feasible to develop such an international multicenter palliative care patient study protocol which meets the nuanced requirements of different national ethical and research governance processes, whilst applying the same data collection and scientific analysis procedures across national boundaries.

We realise that three months is a rather arbitrary period to follow patients who may have a much longer or shorter palliative care trajectory. Identifying those who are in the last year of life, yet functioning well enough to engage with and complete the study over a three month period can be problematic. This challenges us to collect as complete information as possible about experiences of patients throughout their entire palliative care trajectory and to warrant accurate inclusion of patients.

Conclusion

This study will provide valuable data about patients', family and professional caregivers' experiences with various IPC initiatives, including quality of care, quality of life, symptoms, burden and reward of care giving, relationships with and collaboration between professional caregivers. These data will provide important insights into what constitutes best practice, as perceived by those using and providing IPC services, across a range of

different health economies in Europe. This knowledge will add to the scientific evidence for IPC services internationally and will contribute to improvements in the quality of care and the quality of living and dying of severely ill patients and their relatives in Europe.

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3

Integrated palliative care networks from the perspectives of patients

A cross-sectional explorative study in five European countries

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Abstract

Background

Although examining perspectives of patients on integrated palliative care organisation is essential, available literature is largely based on administrative data or healthcare professionals' perspectives.

Aim

(1) Providing insight into the composition and quality of care networks of patients receiving palliative care and (2) describing perceived integration between healthcare professionals within these networks and its association with overall satisfaction.

Design

Cross-sectional explorative design.

Setting/participants

We recruited 157 patients (62% cancer, 25% chronic obstructive pulmonary disease, 13% chronic heart failure, mean age 68 years, 55% female) from 23 integrated palliative care initiatives in Belgium, Germany, the United Kingdom, Hungary and the Netherlands.

Results

About 33% reported contact with a palliative care specialist and 48% with a palliative care nurse. Relationships with palliative care specialists were rated significantly higher than other physicians ($p < 0.001$). Compared to patients with cancer, patients with chronic obstructive pulmonary disease (odds ratio = 0.16, confidence interval (0.04; 0.57)) and chronic heart failure (odds ratio = 0.11, confidence interval (0.01; 0.93)) had significantly lower odds of reporting contact with palliative care specialists and patients with chronic obstructive pulmonary disease (odds ratio = 0.23, confidence interval (0.08; 0.71)) had significantly lower odds of reporting contact with palliative care nurses. Perceptions of main responsible healthcare professionals or caregivers in patient's care networks varied across countries. Perceived integration was significantly associated with overall satisfaction.

Conclusion

Palliative care professionals are not always present or recognised as such in patients' care networks. Expert palliative care involvement needs to be explicated especially for non-cancer patients. One healthcare professional should support patients in understanding and navigating their palliative care network. Patients seem satisfied with care provision as long as continuity of care is provided.

What is already known about the topic?

- Although there have been major improvements in the development of (specialist) palliative care services during the last decade, accessibility to services is still often unevenly distributed across countries and disease groups.
- It can be challenging for patients with cancer to have an overview of their care and to know who their key worker is.

What this paper adds?

- Although patients were recruited from integrated palliative care initiatives, it was uncommon for many of them to report on specialist palliative care professionals within their care networks, especially for patients with chronic obstructive pulmonary disease and chronic heart failure as well as patients from generalist palliative care initiatives.
- This international study shows that patients may have different understandings of the organisation of their care (network) than healthcare professionals. Therefore, it can be challenging for patients to have insight into who is involved in their care network, what are the specific roles of healthcare professionals (e.g. palliative care specialists) and who is the main healthcare professional responsible for their care.
- Notwithstanding differences in the organisation of care networks between different integrated palliative care networks or diagnostic groups, patients generally seem to be satisfied especially with their relationships with palliative care professionals and with care provision as long as continuity of care is provided.

Implications for practice, theory or policy

- The study suggests that palliative care professionals are not always present in care networks or recognised as such by patients. Therefore, the involvement of expert palliative care needs to be explicated, especially for non-cancer patients.
- The roles of different healthcare professionals in patients' palliative care networks need to be clear for patients as well as who is their first point of contact in case of needs.
- One healthcare professional working in the integrated palliative care initiative should have an overview of the patient's palliative care network and support patients in navigating through this network should they need this.

Background

Integrated palliative care is increasingly recognised as a beneficial approach both in terms of patient outcomes^{1, 2} and costs³. However, the best way to organise it is still a point of discussion⁴. Since patients are the direct users of palliative care services, examining their perspectives on integrated palliative care organisation is essential. Although literature about palliative care organisation is available, this is largely based on administrative data or the perspectives of healthcare professionals (HCPs).

For example, the European Association for Palliative Care has published a White Paper providing a normative framework for hospice and palliative care in Europe including requirements for palliative care services^{5, 6}. The Paper distinguishes between a general palliative care approach and specialist palliative care. A general palliative care approach would be used in settings and services that occasionally or even frequently treat palliative care patients, but do not provide palliative care as the main focus of their work. Specialist palliative care is provided by specialised palliative care professionals who treat patients with more complex problems^{5, 6}. In addition to this framework, several studies evaluated the current integration and developments of palliative care services in European countries and beyond. Examples are Pivodic et al.,⁷ Centeno et al.,⁸ Woitha et al.,⁹ and Tanuseputro et al.¹⁰. They found that there have been major improvements in the development of (specialist) palliative care services during the last decade, but that accessibility to services is still often unevenly distributed across countries and disease groups.

In contrast to the abovementioned literature, studies examining integrated palliative care organisation from the patient perspective are limited. Analysing care networks of patients enables examining the organisation of care as well as the quality and potential shortcomings from a patient perspective. A social network approach may be useful here. Social network analysis is based on the notion that individuals are embedded in 'thick webs of social relations and interactions'¹¹. Therefore, studying the nature of relationships and interactions between individuals within a network enables explaining social phenomena or outcomes¹². During the last decades, several approaches towards social network analysis have been developed ranging from merely technical procedures using mathematical methods to quantify networks dynamics and explain outcomes to qualitative approaches allowing for in-depth description of network dynamics and explanation for social phenomena¹². A number of studies focused on the constitution of social support networks of patients^{13, 14} or on continuity of palliative care for children¹⁵. Furthermore, Jarret et al.¹⁶ extensively investigated palliative care networks of patients with cancer. They found that these can be very complex and hence that it can be very challenging for patients to have an overview of their care and to know who their key worker is. However, this study was only conducted with patients in the United Kingdom. As patient's care networks in the last phase of life may differ across countries⁷⁻⁹, due to, for example, regional organisation and development of palliative care, it is useful to consider the organisation of patients' care networks from an international perspective.

This article therefore aims (1) to provide insight into the composition and quality of care networks of patients receiving palliative care within several integrated palliative care initiatives in five European countries from a patient perspective and (2) to describe to what extent integration between HCPs within these networks is perceived by patients and whether this is associated with overall satisfaction with care provision.

Methods

Design

This explorative study uses a cross-sectional design. The study was part of a European multiple embedded case study (InSup-C)¹⁷. The STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) checklist for observational, cross-sectional studies¹⁸ was used to report our data.

Participants and sampling

Patients were recruited from 23 eligible integrated palliative care initiatives in Belgium, Germany, the United Kingdom, Hungary and the Netherlands. Inclusion criteria for integrated palliative care initiatives have been published elsewhere¹⁹. Patients were selected by their treating HCPs based on inclusion criteria: life expectancy of maximum 1 year, advanced cancer, chronic obstructive pulmonary disease (COPD) with Gold stage IV classification or chronic heart failure (CHF) with *New York Heart Association* (NYHA) classification stage III–IV. If patients expressed interest in participation, they received further information from the researcher who would collect the data. After providing written consent, participants took part in a semi-structured interview and completed questionnaires at baseline and after 3 months. For this study, we used only the baseline data from the questionnaires, because at month 3 there were too much missing data (response rate 53%) to do useful analyses. Attrition was mainly due to death and poor health of the patient. Because the InSup-C study addressed the topic of integrated palliative care, patients were recruited from a pre-selection of integrated palliative care initiatives where integration was already visible and not 'at random'. Therefore 'country' as a variable in the results section refers to the pre-selection of integrated palliative care initiatives in that country.

Data collection

Demographic data were collected at baseline. The Palliative care Outcome Scale (POS)²⁰ was used to measure patients' overall condition. Questions include 5-point Likert scales ranging from 0 to 4. To examine the organisation and quality of patients' care networks, we used a social network analysis approach.¹¹ Although the qualitative results of this study on the experiences of seriously ill patients and their family caregivers with the care they received from HCPs in the patients' care network have been published elsewhere,¹⁹ the

focus of this study was to quantitatively explore the composition of patients' care networks, perceived integration and its relation to perceived satisfaction. Therefore, a basic approach of social network analysis was used. A social network analysis questionnaire was developed by the Dutch research team based on existing literature²¹⁻²³. A preliminary version of the questionnaire was discussed, adjusted and subsequently approved within the international InSup-C research team. The questionnaire contains 12 questions about HCPs in the patient's care network, collaboration and continuity within the network and the quality of relationships with, and quality of care provided by, individual HCPs (Appendix 1). The questions include dichotomous answer categories, 5-point Likert scales ranging from 0 (*excellent*) to 4 (*poor*) and from 0 (*completely disagree*) to 4 (*completely agree*) as well as open answer questions. The social network analysis questionnaire served as the basis for semi-structured interviews as part of the previously mentioned qualitative study¹⁹. In these interviews, the answers given to the social network analysis questionnaire were further explored. This study reports the results of the social network analysis questionnaire.

Perceived integration between HCPs in care networks was measured using social network analysis questions 5–9 (based on the Nijmegen Continuity of Care questionnaire²¹) containing statements about collaboration and continuity of care within the care network. Overall satisfaction with care provision was measured using the Canadian Health Care Evaluation Project Questionnaire Lite (Canhelp Lite).²⁴ The questionnaire includes five domains: Relationship with the doctors, Illness management, Communication, Decision-making and Feeling at peace. Questions contain 5-point Likert scales ranging from 0 (*very dissatisfied*) to 4 (*very satisfied*). For the analysis, we used the Canhelp Lite overall summary score which is the unweighted average of all answered questions.

Data were collected between June 2014 and August 2015. Review committee approvals were obtained in all participating countries, if required. Details of ethics approvals have been reported elsewhere¹⁹.

Data analysis

We examined differences in characteristics (gender, age, diagnosis, country, generalist versus specialist palliative care initiative) of those who reported contact with a particular HCP compared to those who did not. Chi-square tests (or Fisher's exact tests if necessary) were used to determine statistical significance. For the relevant HCPs, we used multiple logistic regression (Enter method) to examine associations of these characteristics with the outcome 'having contact with a particular HCP'. To examine statistical significance of differences between means, we used *T*-tests and analysis of variance (ANOVA) tests.

To examine the association between perceived integration and overall satisfaction, we first examined bivariate associations between the individual determinants (social network analysis questions 5–9, age, gender, diagnosis, country, generalist vs specialist palliative care initiative, having contact with a particular HCP) and the outcome overall satisfaction. Subsequently, we conducted multiple regression analysis (Enter method) to find determinants

for overall satisfaction. Overall, we used statistical significance level $p = 0.05$. To support statistical analysis, we used IBM SPSS Statistics 22.

Results

Participant characteristics

The response rate at baseline was 100%. In all, 157 patients participated in the study of which there were 15 in Belgium, 34 in Germany, 35 in the United Kingdom, 42 in Hungary and 31 in the Netherlands (Table 1). The majority of patients had cancer ($n = 97$, 62%), 39 patients had COPD (25%) and 21 patients had CHF (13%). In Belgium, Germany and the Netherlands, the majority of patients had cancer while in Hungary and the United Kingdom a substantial number of patients had COPD or CHF. The mean age of all patients was 68 years, and more than half were female ($n = 87$, 55%). The time spent in bed or laying down during the daytime and POS mean sum scores indicate that patients' overall condition was reasonable at the time of the interview given their palliative background. Moreover, POS mean sum scores did not differ significantly between diagnostic groups ($p = 0.517$) and countries of origin ($p = 0.392$). The majority of patients were living at home ($n = 144$; 92%) when completing baseline questionnaires. Integrated palliative care initiatives selected included specialised and general palliative care services based at hospitals, hospices or in home care in conjunction with primary and secondary care. The types of initiatives selected have been described elsewhere.¹⁹

Most frequently reported HCPs and caregivers in patients' care networks

Specialist palliative care. A third of all patients reported contact with a palliative care specialist ($n=51$; 33%; Table 2). Almost half of the patients reported contact with a palliative care nurse ($n = 75$; 48%).

General palliative care. Most patients reported contact with a general practitioner (GP) ($n = 138$; 88%; Table 2). One-third reported contact with an oncologist ($n = 55$; 35%) or with a specialist other than oncologist, cardiologist or pulmonologist ($n = 52$, 33%). Less than one-fifth reported contact with a cardiologist ($n = 26$; 17%) or pulmonologist ($n = 28$; 18%). A quarter of the patients reported contact with a home care nurse ($n = 39$; 25%).

Patients rated the quality of their relationship with physicians and the quality of care provision received from these physicians between reasonable and good. Relationships with palliative care specialists were rated significantly higher compared to other physicians ($p < 0.001$). The quality of relationships with nurses and the quality of care provision received from these nurses were rated between good and excellent. We found no significant difference between patients' relationships with palliative care nurses and other nurses ($p = 0.395$).

Table 1 Baseline patient characteristics by country.

	Belgium	Germany	United Kingdom	Hungary	The Netherlands	Total
Patients N	15	34	35	42	31	157
Age, years (N = 153), mean (SD)	69 (12)	69 (12)	66 (12)	68 (8)	70 (8)	68 (10)
Gender, N (%)						
Female	8 (53)	18 (53)	22 (63)	25 (60)	17 (55)	87 (55)
Male	7 (47)	16 (47)	13 (37)	17 (40)	14 (45)	70 (45)
Diagnosis, N (%)						
Cancer	12 (80)	31 (91)	18 (51)	14 (33)	22 (71)	97 (62)
COPD	3 (20)	3 (9)	10 (29)	17 (41)	6 (19)	39 (25)
CHF	0	0	7 (20)	11 (26)	3 (10)	21 (13)
Time spent in bed or lying down during the daytime (N = 156), N (%)						
Hardly ever in bed	7 (47)	15 (46)	8 (23)	19 (45)	7 (23)	56 (36)
Less than half a day	3 (20)	10 (30)	15 (43)	9 (21)	17 (55)	54 (35)
More than half a day	3 (20)	5 (15)	12 (34)	11 (26)	4 (13)	35 (22)
All day	2 (13)	3 (9)	0	3 (7)	3 (10)	11 (7)
Pos sum score^a (N = 132), mean (SD)	15 (7)	14 (7)	11 (6)	12 (7)	12 (6)	12 (6)
Place of residence at baseline, N (%)						
Home	13 (87)	31 (91)	34 (97)	39 (93)	27 (87)	144 (92)
Nursing home	2 (13)	0	1 (3)	1 (2)	4 (13)	8 (5)
Hospital	0	3 (9)	0	0	0	3 (2)
Hospice	0	0	0	2 (5)	0	2 (1)
Type of integrated palliative care initiative,^b N (%)						
Specialised home care palliative care support service	10 (67)	0	0	0	0	10 (6)
Specialised palliative care service based in hospital in conjunction with specialised palliative home care services and/or other primary and secondary care services	0	34 (100)	0	12 (29)	12 (39)	58 (37)
Specialised palliative care service based in hospice in conjunction with primary and secondary care	0	0	26 (74)	12 (29)	0	38 (24)

Table 1 Continued.

	Belgium	Germany	United Kingdom	Hungary	The Netherlands	Total
General palliative home care service in conjunction with specialised palliative care (support) service	5 (33)	0	8 (23)	12 (29)	4 (13)	29 (18)
General palliative care nursing home service based in hospital in conjunction with secondary care	0	0	1 (3)	0	5 (16)	6 (4)
General palliative care service based in hospital in conjunction with primary care	0	0	0	6 (14)	10 (32)	16 (10)

SD: standard deviation; COPD: chronic obstructive pulmonary disease; CHF: chronic heart failure; POS: Palliative care Outcome Scale; HCP: healthcare professional.

Due to rounding up some percentages do not add up to 100%.

^aPOS sum score ranges from 0 (*good overall condition*) to 40 (*very bad overall condition*).

^b*Specialised* means that the majority of HCPs involved in the initiatives are palliative care specialists, while *general* means that of the HCPs involved in the initiative only a few are palliative care specialist or have received basic palliative care training.

Additional care. Less than one-third of the patients reported contact with a physiotherapist ($n = 41$; 26%). Between one-tenth and one-fifth reported contact with another HCP such as spiritual worker ($n = 28$; 18%), psychologist ($n = 22$; 14%) or social worker ($n = 17$; 11%; Table 2). Patients rated their relationship with additional HCPs between reasonable and excellent.

Informal and voluntary care. Most patients reported having a family caregiver ($n = 136$; 87%; Table 2). Patients rated their relationship with the family caregiver between good and excellent. Only 14 patients reported contact with a volunteer (9%) with whom they rated their relationship between reasonable and excellent.

Differences between diagnostic groups and countries for reporting contact with a particular HCP

Logistic regression (Table 3) confirmed the differences between diagnostic groups and countries for reporting contact with particular HCPs displayed in Table 2. Patients with COPD (odds ratio (OR) = 0.16, confidence interval (CI) (0.04; 0.57)) and CHF (OR = 0.11, CI (0.01; 0.93)) had significantly lower odds of reporting contact with a palliative care specialist compared to those with cancer (the reference group). Patients with COPD

Table 2 Most frequently reported people in patients' care networks from the perspectives of patients living at home or in a nursing home.

	Specialist palliative care		General palliative care								Additional care				Informal and volunteer care	
	PC specialist	PC nurse	All Physicians	GP	Onc	Car	Pul	Specialist other than onc/car/pul	All Nurses	Home Care Nurse	Physiotherapist	Spiritual worker	Psychologist	Social worker	Family caregiver	Volunteer
Contact with actor, N (%) (N=157)	51 (33)	75 (48)	151 (96)	138 (88)	55 (35)	26 (17)	28 (18)	52 (33)	122 (78)	39 (25)	41 (26)	28 (18)	22 (14)	17 (11)	136 (87)	14 (9)
<i>Per country, N (%)</i>																
Belgium (N=15)	1 (7)	11 (73)	14 (93)	14 (93)	6 (40)	2 (13)	2 (13)	1 (7)	14 (93)	12 (80)	6 (40)	4 (27)	4 (27)	1 (7)	14 (93)	3 (20)
Germany (N=34)	29 (85)	22 (65)	33 (97)	32 (94)	17 (50)	2 (6)	3 (9)	8 (24)	26 (77)	5 (15)	9 (27)	7 (21)	5 (15)	5 (15)	26 (77)	3 (9)
United Kingdom (N=35)	2 (6)	28 (80)	35 (100)	35 (100)	17 (49)	6 (17)	6 (17)	6 (17)	35 (100)	10 (29)	1 (3)	7 (20)	5 (14)	4 (11)	29 (83)	2 (6)
Hungary (N=42)	7 (17)	0	41 (98)	30 (98)	7 (17)	11 (26)	11 (26)	27 (64)	22 (52)	2 (5)	18 (43)	3 (7)	7 (17)	6 (14)	39 (93)	3 (7)
The Netherlands (N=31)	12 (39)	14 (45)	28 (90)	27 (87)	8 (26)	5 (16)	6 (19)	10 (32)	25 (81)	10 (32)	7 (23)	7 (23)	1 (3)	1 (3)	28 (90)	3 (10)
<i>Per diagnostic group, N (%)</i>																
Cancer (N=97)	46 (47)	58 (60)	95 (98)	89 (92)	54 (56)	5 (5)	6 (6)	25 (26)	74 (76)	23 (24)	16 (17)	20 (21)	14 (14)	9 (9)	87 (90)	10 (10)
CHF (N=21)	1 (5)	7 (33)	20 (95)	19 (91)	0	17 (81)	0	10 (48)	16 (76)	6 (29)	7 (33)	2 (10)	5 (24)	1 (5)	16 (76)	0
COPD (N=39)	4 (10)	10 (26)	36 (92)	30 (77)	1 (3)	4 (10)	22 (56)	17 (44)	32 (82)	10 (26)	18 (46)	6 (15)	3 (8)	7 (18)	33 (85)	4 (10)
Rating of quality of relationship with HCP, mean (SD) ^a	0.8 (0.7)	0.8 (0.7)	1.2 (0.8)	1.4 (1.0)	1.1 (1.1)	1.5 (1.2)	1.7 (1.0)	1.1 (1.1)	0.9 (0.7)	1.1 (0.9)	1.1 (0.9)	1.0 (0.9)	0.9 (1.2)	1.5 (0.9)	0.4 (0.7)	0.9 (0.8)
Difference between relationship with respective HCP and PC specialist/nurse, p-value [95% CI]	n/a	n/a	<0.001* [-0.92; -0.37]	<0.001* [-1.06; -0.40]	0.249 [-0.83; 0.23]	0.141 [-0.25; 0.75]	0.034* [-1.88; -0.12]	0.088 [-1.24; 0.10]	0.395 [-0.47; 0.19]	0.193 [-0.83; 0.18]	n/a	n/a	n/a	n/a	n/a	n/a
Rating of quality of care provision by HCP, mean (SD)	0.8 (0.7)	0.8 (0.8)	1.1 (0.9)	1.3 (1.0)	1.1 (1.1)	1.1 (1.1)	1.5 (1.1)	1.1 (1.1)	1.0 (0.8)	1.1 (0.9)	1.2 (0.9)	1.0 (0.9)	1.0 (1.2)	1.6 (1.1)	0.4 (0.7)	1.1 (1.0)

PC specialist = palliative care specialist, which includes: GP palliative care specialist from the palliative home care team, palliative care specialist/consultant and hospice physician; PC nurse = palliative care nurse, which includes: nurse specialised in palliative care and nurse practitioner palliative care; GP = general practitioner; Onc = oncologist; Car = cardiologist; Pul = pulmonologist; SD: standard deviation; CI: confidence interval.

Percentages shown are percentages of the total number of patients (N) displayed in the first column.

^aRatings of quality of relationship as well as quality of care provision could range from 0 (*excellent*) to 4 (*poor*).

*significant at 0.05 level.

(OR = 0.23, CI (0.08; 0.71)) had significantly lower odds of reporting contact with a palliative care nurse than those with cancer. Furthermore, patients with COPD also had significantly lower odds of reporting contact with a GP (OR = 0.30, CI (0.11; 0.85)). However, patients with CHF (OR= 3.96 (1.03; 15.31)) had significantly higher odds of reporting contact with a home care nurse than those with cancer. Both patients with CHF (OR= 4.83, CI (1.24; 18.79)) and COPD (OR = 7.09, CI (2.47; 20.33)) had significantly higher odds of reporting contact with a physiotherapist than those with cancer.

Logistic regression (Table 3) also demonstrated that after correction for diagnostic group, patients from German (OR = 86.84, CI (8.94; 844.06)) and Dutch initiatives (OR = 11.31, CI (1.27; 100.59)) had significantly higher odds of reporting contact with a palliative care specialist compared to those in Belgium (the reference group). In Hungarian initiatives, none of the patients reported contact with a palliative care nurse. In other countries, the odds of reporting contact with a palliative care nurse did not differ significantly from those in the Belgium initiatives. Furthermore, in all countries patients from the selected

Table 3 Multiple logistic regression for the association between having/not having contact with respective healthcare professional and diagnosis as well as country.

Determinant	Palliative care specialist		Palliative care nurse		General practitioner		Home care nurse		Physiotherapist	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Diagnosis										
Cancer	1.00	0.005*	1.00	0.038	1.00	0.065	1.00	0.106	1.00	0.001*
CHF	0.11 [0.01;0.93]	0.042*	0.63 [0.12;3.34]	0.586	0.85 [0.17;4.34]	0.849	3.96 [1.03;15.31]	0.046*	4.83 [1.24;18.79]	0.023*
COPD	0.16 [0.04;0.57]	0.005*	0.23 [0.08;0.71]	0.011*	0.30 [0.11;0.85]	0.023*	2.11 [0.72;6.16]	0.173	7.09 [2.47;20.33]	<0.001*
Country^a										
Belgium	1.00	<0.001*	1.00	0.034*	n/a	n/a	1.00	<0.001*	1.00	0.019*
Germany	86.84 [8.94;844.06]	<0.001*	0.54 [0.13;2.20]	0.385			0.05 [0.01;0.22]	<0.001*	0.65 [0.17;2.54]	0.534
UK	1.24 [0.10;15.21]	0.866	1.90 [0.41;8.78]	0.410			0.07 [0.01;0.31]	0.001*	0.02 [0.00;0.21]	0.001*
Hungary	6.40 [0.67;60.88]	0.106	0.00 [0.00]	0.997			0.01 [0.00;0.05]	<0.001*	0.46 [0.11;1.94]	0.290
Netherlands	11.31 [1.27;100.59]	0.030*	0.28 [0.07;1.16]	0.080			0.10 [0.02;0.45]	0.003*	0.32 [0.07;1.39]	0.128

OR: odds ratio; CI: confidence interval; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease.

To limit the number of variables in the regression model due to the small sample size and since age and gender were not significant for any of the healthcare professionals, we did not include these two variables in the final regression model.

^aCountry was chosen as the reference group, since this was the first category within variable country.^aCountry as a variable refers to the selection of integrated palliative care initiatives in that country, not directly to the whole country.

*Significant at 0.05 level.

initiatives reported significantly lower odds of reporting contact with a home care nurse than those in Belgium. In addition, patients in the United Kingdom (OR = 0.02 (0.00; 0.21)) had significantly lower odds of reporting contact with a physiotherapist than those in Belgium initiatives.

Patients' perceptions of main responsible HCP or caregiver

We found large variations between patients' answers to the question 'Who, do you think, is the main responsible caregiver of all caregivers you receive care from? (i.e. the person(s) who decide(s) how your care is being organised)?' (Table 4). In Hungarian and Dutch initiatives, the largest proportion of patients reported hospital specialists to be responsible for organising their care. In German initiatives, most patients reported family caregivers to be the central person in their care network. Patients from initiatives in the United Kingdom most often reported nurses or hospital specialists as the central HCP. Furthermore, a number of patients in Belgium, the United Kingdom, the Netherlands and Hungary perceived that more than one person (e.g. patient, family caregiver, nurse and GP) were responsible for organising their care.

Table 4 Top 3 "Who, do you think, is the main responsible caregiver of all caregivers you receive care from? (i.e. the person(s) who decide(s) how your care is being organised)?" by country.

	Belgium	Germany	United Kingdom	Hungary	The Netherlands
1	More than one healthcare professionals ^a (n=4, 27%)	Family caregiver (n=12; 35%)	Nurse (n= 10, 29%)	Hospital specialist (n= 22, 52%)	Hospital specialist (n=11, 36%)
2	Nurse (n= 2, 13%), GP (n= 2, 13%), Family Caregiver (n= 2, 13%)	Patient (n=4, 12%)	Hospital specialist (n=8, 23%)	More than one healthcare professionals ^a (n=5, 12%)	More than one healthcare professionals ^a (n=5, 16%)
3	-	GP (n= 3, 9%), Palliative Care specialist (n= 3, 9%)	More than one healthcare professionals ^a (n= 6, 17%)	Don't know (n=4, 10%)	GP (n=3, 10%)

GP: general practitioner.

^aMore than one healthcare professionals mainly includes a combination of 2-4 of the following HCPs: family caregiver, patient, nurse (home care/specialised), GP, palliative care physician, hospital specialist.

Integration between HCPs and its association with overall satisfaction

Generally, patients perceived moderate to high integration between HCPs in their care networks and almost no friction. Furthermore, on average patients were quite satisfied about the care they received (see Table 5).

We did not find significant associations between overall satisfaction and generalist versus specialist palliative care initiative or having contact with particular HCPs. The multiple regression analysis in which we examined predictors for overall satisfaction with care showed a weak ($R^2 = 0.31$), but significant association between overall satisfaction and independent variables country, diagnosis, age, gender and perceived integration. The relation was mainly due to perceived integration (social network analysis questions 6 and 9) and country (Table 6).

Table 5 Social network analysis questions about perceived integration between healthcare professionals involved in the care networks of patients and Canhelp Lite questionnaire overall summary score.

	Mean	SD
5 These caregivers appear to work together very well ^a	3.0	0.9
6 The care given by these caregivers appears to be well-connected ^a	2.9	1.0
7 These caregivers pass on information to each other well ^a	2.9	1.0
8 These caregivers always know very well what the other caregivers have done ^a	2.7	1.1
9 Sometimes, I perceive friction between caregivers ^a	1.2	1.2
Canhelp Lite overall summary score ^b	3.0	0.6

SD: standard deviation.

^aScale ranges from 0 (*strongly disagree*) to 4 (*strongly agree*).

^bScale ranges from 0 (*not at all satisfied*) to 4 (*completely satisfied*).

Table 6 Multiple linear regression model for the association between overall satisfaction with care and diagnosis, country, age, gender and social network analysis questions 6 and 9.

Determinant	B [95% CI]	p-value
Diagnosis		
Cancer	Reference	
CHF	0.11 [-0.19; 0.41]	0.470
COPD	-0.08 [-0.32; 0.16]	0.531
Country^a		
Belgium	Reference	
Germany	0.51 [0.03; 0.98]	0.037*
UK	0.33 [-0.02; 0.68]	0.068
Hungary	0.34 [-0.02; 0.70]	0.067
Netherlands	0.00 [-0.36; 0.36]	0.981
Age	0.00 [-0.01; 0.01]	0.441
Gender	-0.07 [-0.27-0.13]	0.479
Social network analysis question 6 “The care given by these caregivers appears to be well-connected”^b	0.19 [0.08; 0.29]	<0.001*
Social network analysis question 9 “Sometimes I perceive friction between caregivers”^b	-0.10 [-0.19; -0.01]	0.030*

CI: confidence interval; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease.

Belgium was chosen as the reference group, since this was the first category within the variable country.

^a ‘Country’ as a variable refers to the selection of integrated palliative care initiatives in that country, not directly to the whole country.

^b The separate social network analysis questions 5-9 significantly associated with overall satisfaction. However, since these questions mutually correlated we decided to only include questions 6 and 9 in the multiple regression model based on the highest coefficient of determination (R^2).

* significant at 0.05 level.

R^2 of the model = 0.31.

Discussion

This study examined perspectives of patients receiving care from several integrated palliative care initiatives in five European countries on the organisation and quality of their care networks. We found large differences between patient’s reports on the organisation of their care networks for different diagnostic groups and countries of origin of the integrated palliative care initiatives involved. Notwithstanding, overall satisfaction was high and did not vary greatly. Moreover, patients’ perceptions of integration between HCPs involved in their care networks significantly affected overall satisfaction.

Although patients were recruited from integrated palliative care initiatives, it was uncommon for many patients to report on specialist palliative care professionals within their care networks, especially for those with COPD, CHF and patients from generalist palliative care initiatives. Other studies found that palliative care is unevenly spread between disease groups and predominantly includes services for patients with cancer^{7, 10}. However, differences found in this study also related to the type of integrated palliative care initiatives from which patients were recruited (generalist or specialist). For patients who were recruited from specialist palliative care initiatives, the involvement of a palliative care specialist in their care network was apparently more clear than for patients recruited from generalist palliative care initiatives.

Several studies show that palliative care is increasingly provided by generalist HCPs such as GPs^{7, 25} or hospital clinicians²⁶. However, patients may not always be aware of this, let alone that they know what palliative care means. This study shows that patients may have different understandings of the organisation of their care (network) than HCPs. Therefore, it can be challenging for patients to have insight into who is involved in their care network¹⁶, what are the specific roles of HCPs, for example, palliative care specialists²⁷ and who is the main responsible HCP for their care. HCPs involved in integrated palliative care initiatives should be aware of potential needs of patients to clarify roles of specific key workers and to support them in navigating the health system.

Patients rated their relationships with palliative care specialists slightly higher compared to other physicians, and palliative care services seemed to be organised differently across countries. Nevertheless, overall satisfaction with care provision was not significantly different between diagnostic groups, HCPs, generalist versus specialist palliative care initiative and most countries. In addition, we did find a significant association between integration and satisfaction. These results suggest that it does not matter so much to patients who provides care or how their care is organised, as long as HCPs can provide continuity of care. A recent review²⁸ including 19 studies supports this finding showing that continuity of care aspects (being available as an HCP and providing security) are essential for achieving positive patient experiences with palliative care.

Strengths and limitations

This study provides international insight into care networks of patients within several integrated palliative care initiatives in five European countries from the perspectives of patients. Since the results in this study are reported by patients themselves in different countries, they are limited by self-reporting bias and potential ambiguity in the interpretation of questions about roles and responsibility of palliative care or other HCPs and differences in the national healthcare systems. Nevertheless, we think these data are valuable, as patient perspectives about their care networks are likely to differ from that described by HCPs or family caregivers. Since patients probably do not always understand how their healthcare is organised, evaluating patients' views could identify gaps, for

example, in their knowledge about the organisation or coordination of their care network and could therefore function as a trigger for improvement.

The association between integration and satisfaction was weak. Probably with only four questions to measure integration, we might not have captured integration completely. This confirms the literature suggesting that integration is only one among several aspects influencing satisfaction with care. For example, several review studies²⁸⁻³⁰ suggest that factors such as adequate symptom control, communication and shared care are crucial for satisfaction with palliative care.

The conclusions drawn from this study need to be taken with caution, since the sample included relatively small numbers that do not aim to be representative for whole countries with their varying healthcare organisations. This was an exploratory study in which we aimed to explore important features of the palliative care networks as reported by patients, rather than striving to test hypotheses. Analyses done are to be seen as an attempt to gain insight into the data within in this specific sample. Significant outcomes in this study should be therefore interpreted with care. Although the results are not representative for whole countries and diagnostic groups, these analyses provide information on how palliative care networks are built from a patient perspective and how they operate between different disease groups. A study with a representative sample of each country and diagnostic group, however, is needed in order to further investigate this topic.

Conclusion

This study provides insight into perspectives of patients with advanced cancer, COPD or heart failure receiving care by several integrated palliative care initiatives in five European countries on the organisation and quality of their care networks. Notwithstanding differences in the organisation of care networks between different integrated palliative care networks or diagnostic groups, patients generally seem to be satisfied especially with their relationships with palliative care professionals and with care provision as long as continuity of care is provided. The study suggests that palliative care professionals are not always present in care networks or recognised as such by patients. Therefore, the involvement of expert palliative care needs to be explicated especially for non-cancer patients. Furthermore, the roles of different HCPs in patients' palliative care networks need to be clear for patients as well as who is their first point of contact in case of needs. One HCP working in the integrated palliative care initiative should therefore have an overview of the patient's palliative care network and support patients in navigating through this network should they need this.

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4

How continuity of care is experienced within the context of integrated palliative care:

A qualitative study with patients and family caregivers in five European countries

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Abstract

Background

Patients with advanced diseases often experience deficient continuity of care. Although integrated palliative care promotes continuity of care, it is not clear how it can be optimized to improve continuity of care experiences.

Aim

To examine how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in five European countries.

Design

We adopted a longitudinal qualitative study design including two interviews (interval 3 months) with patients and family caregivers focusing on how health care professionals responded to their needs. Interviews were audio-recorded and transcribed verbatim. Analysis involved a two-step qualitative content approach.

Setting/participants

A total of 22 integrated palliative care initiatives (established local palliative care collaborations) were selected in Belgium, Germany, Hungary, the Netherlands and the United Kingdom. We recruited 152 patients (63% cancer, 24% chronic obstructive pulmonary disease, 13% heart failure; life expectancy <1 year; mean age 68 years, 56% female) and 92 family caregivers (mean age 61 years, 66% female).

Results

Trusted relationships with a small number of key health care professionals to receive tailored care and easily access help were essential. Relational continuity was often deficient, especially with general practitioners. Although informational and management continuity was often lacking in care provision, collaborative integrated palliative care initiatives were related to consistent and coherent care.

Conclusion

Patients and family caregivers most likely experience continuity of care by having a small number of trusted health care professionals who are available, provide multidisciplinary care and regularly transfer information to all health care professionals involved. Optimizing continuity of care requires further integration of integrated palliative care initiatives with other health care professionals involved in the patients' care networks.

What is already known about the topic?

- Integrated palliative care has the potential to improve continuity of care experiences which are often at stake within the context of palliative care.
- Collective team approaches have added value for patients' and family caregivers' experiences of security.

What this paper adds?

- For patients and family caregivers, it is essential to have trusted relationships with a small number of key health care professionals in order to receive tailored care and easily seek help when needed.
- Multidisciplinary care provision could jeopardize patients' and family caregivers' need to have trusted relationships with key health care professionals, particularly those with general practitioners.
- Collaborative integrated palliative care initiatives are likely to improve patients' and family caregivers' experiences of informational and management continuity.

Implications for practice, theory or policy

- Integrated palliative care initiatives should identify a small number of trusted key health care professionals who are readily available and contactable by patients and family caregivers.
- General practitioners should be more involved in leading multidisciplinary care provision for patients with palliative care needs.
- Integration of integrated palliative care initiatives with health care professionals involved in patient's care networks should be enhanced in order to optimize experiences of informational and management continuity.

Introduction

Continuity of care is associated with lower rates of emergency department visits^{1, 2}, decreased hospital deaths^{3, 4} and supportive needs being met⁵. It is a key issue in health care policy and organization^{6, 7} and is crucial for patient experiences with health care^{8, 9}. However, continuity of care is often at stake in care provision for patients with advanced diseases who usually receive care from multiple health care professionals⁹⁻¹³. Lack of continuity of care can cause undesired experiences with palliative care provision, for example, feeling unsafe during illness transitions⁹, patients being transferred between multidisciplinary teams¹¹ and suboptimal support for problems and needs^{12, 13}. Integrated palliative care has been increasingly proposed in order to achieve continuity of care for patients with advanced diseases^{14, 15}. Integrated palliative care focuses on coordinating care around the needs of patients with advanced illnesses^{16, 17}. Integrated palliative care approaches have shown promising results, not only in terms of continuity of care but also with regard to quality of life, survival rates and cost-effectiveness^{15, 18-20}. However, it is not clear how integrated palliative care efforts improve outcomes such as continuity of care²¹ making it difficult to inform health care policies²². Extensive research has been conducted on how continuity of care is achieved within chronic disease management and mental health²³⁻²⁸. This has resulted in a widely recognized definition of continuity of care: ‘the extent to which a series of health care services is experienced as connected and coherent and is consistent with a patient’s health needs and personal circumstances’²⁹. Three interrelated dimensions of continuity of care have been distinguished: (1) relational continuity referring to having ongoing therapeutic relationships with one or more providers, (2) informational continuity referring to the use of information about past events and personal circumstances to make current care appropriate for each individual and (3) management continuity referring to a consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs²⁹. As patients and family caregivers can have an important role in securing continuity^{30, 31}, examining their perspectives on how continuity of care is achieved is essential. Furthermore, continuity of care is a complex multidimensional concept, and therefore obtaining insight into patients’ and family caregivers’ perspectives on this concept requires qualitative investigation^{32, 33}. Limited qualitative research within the context of palliative care suggests that maximized continuity of care at all three levels relates to positive care experiences^{8, 10} and that collective team approaches may have added value³⁴. However, there is a need to further investigate how health care professionals can optimize integrated palliative care to improve continuity of care experiences. Therefore, this article examines how relational, informational and management continuity of care are experienced by patients with advanced cancer, chronic obstructive pulmonary disease (COPD) or heart failure and family caregivers receiving care from integrated palliative care initiatives in five European countries.

Methods

Design

We used a longitudinal qualitative study design which was part of a multiple embedded case study conducted by the European InSup-C project that aimed to identify prerequisites for integrated palliative care³⁵. We choose this design in order to explore the in-depth views of patients and family caregivers about the care they receive from integrated palliative care services and other health care professionals involved over time.

Recruitment

We selected integrated palliative care initiatives in five European countries (Belgium, Germany, Hungary, the Netherlands and the United Kingdom) using uniform selection criteria (Table 1) and an integrated palliative care working definition:

*Bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid.*³⁶

Table 1 Selection criteria for IPC initiatives.

1.	The initiative is an established local palliative care collaboration
2.	The collaboration must contain at least two different organisations
3.	A hospital can be part of that collaboration
4.	Collaborating health care professionals must provide direct patient care (not only an advisory function)
5.	The collaboration has a multidisciplinary background (professionals of different professions must be involved, e.g. physician (specialist, GP), nurse (specialist), social worker, Allied Health Professional, spiritual worker, complementary therapist, others)
6.	The collaboration aims to provide palliative care for one or more target diagnostic groups in the study (Advanced Cancer/ COPD/CHF)

GP: general practitioner; COPD: chronic obstructive pulmonary disease; CHF: congestive heart failure.

We developed these criteria in order to have initiatives that would reflect the cross-sector and multidisciplinary nature of integrated care. From the integrated palliative care initiatives, we recruited patients and their family caregivers using inclusion criteria (Table 2). Respondents were informed about the study by their treating health care professionals. If they expressed interest in participation, they received further information and a consent form from the researcher who would conduct the interview.

Table 2 Inclusion criteria for patients and family caregivers.

General criteria	
1.	18 years or above
2.	Able to communicate in the national language (Dutch, English, German, Hungarian)
3.	Cognitively able to complete questionnaires and to participate in interviews
Specific patient criteria	
1.	The patient's attending doctor answers "No" to the surprise question: "Would you be surprised if the patient died within 1 year?"
2.	Any of the following diagnoses: A) Advanced cancer (cancer with local progression and / or distant metastasis at presentation) B) Severe heart failure in accordance with NYHA classification stage III-IV C) COPD Gold stage IV classification

NYHA: New York Heart Association; COPD chronic obstructive pulmonary disease.

Data collection

After obtaining written consent, patients and family caregivers participated in two semi-structured interviews with an interval of 3 months. Longitudinal interviewing allowed us to explore care experiences over time and confirm findings from the first interview. We developed a uniform interview protocol for patient and family caregiver interviews that was used by all researchers performing the interviews (Appendix 2). The protocol for the patient interviews focused on how health care professionals in patients' care networks responded to their needs and included three sections: (1) problems and needs, (2) relationships with health care professionals in the patient's care network and (3) collaboration between health care professionals. For family caregiver interviews, we used the same protocol, but we asked them to answer the questions about the patient's care from their own perspective. In order to support respondents in reporting their experiences with care provision in a structured way, we used a prompt card method³⁷.

The first two patient interviews were regarded as a pilot study. Since there was no need to change the content of the interview guide, these patients were included in the final sample. Interviews were mainly conducted at home and also at the place where patients resided at that moment (e.g. hospice or rehabilitation department). Interviews took on average 1 hour. If possible we tried to interview patients and family caregivers separately. However, when participants wished the family caregiver or patient to be present when they were interviewed, we asked the one who accompanied the interviewee to respect their perspective. Data were collected between June 2014 and August 2015. Interviews were audio-recorded and transcribed verbatim. Field notes were made during data collection and stored in the national research team's qualitative databases.

Before starting the interviews, one group training was organized for the interviewers to enable them to collect reliable and valid data and to ensure consistency of methodology among countries. Furthermore, to reflect on the data collection and preliminary analysis, monthly Skype meetings were held with the international research team. Research ethics committee approvals were obtained in all countries (Medical Ethics Committee UH Leuven, Belgium S56893/ML11187; NRES Committee North West, Lancaster, United Kingdom 14/NW/0140; Medical Faculty Ethics Committee Rheinische Friedrich-Wilhelms-Universität, Bonn, Germany 014/14; Medical Research Council Scientific and Research Committee, Hungary 21005-2/2014/EKU (194/2014)). However, in the Netherlands the study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO) and so did not require approval from an ethics committee (Medical Research Ethics Committee Arnhem-Nijmegen, The Netherlands 2013/538).

Data analysis

Interview data were analysed using qualitative content analysis³⁸ and comprised two steps: (1) a general analysis of the national data resulting in an international code book and (2) an in-depth analysis on continuity of care.

Step 1: general analysis. Two researchers in each country deductively coded 10 (patient, family caregiver and bereavement) interviews using a priori main themes derived from the interview protocol (Figure 1). Then the same researchers inductively coded these interviews using line-by-line coding. Line-by-line codes were clustered into sub-themes which were compared in a face-to-face meeting. A code book was created during this meeting based on the consented sub-themes. Then all interviews were coded using the code book. Regular Skype meetings were held and electronic correspondence took place in order to refine the code book until no new sub-themes emerged. Qualitative Data Software Nvivo 10 was used in order to support the coding process.

Step 2: in-depth analysis of continuity of care. Since continuity of care emerged as an important theme explaining patients' and family caregivers' experiences with care provision provided by health care professionals we decided to explore this theme in depth. We used Haggerty et al.'s²⁹ continuity of care definition including its three dimensions as described in the introduction as a theoretical framework to allow uniform analysis and enable international comparison. Based on this framework, research teams in each country further analysed the main themes in the code book that were relevant in the context of continuity of care (main themes: relational patient–health care professional, relational family caregiver–health care professional and relational health care professional–health care professional). Quotes were added by the national teams in order to illustrate the findings. The resulting five country-specific analyses were subsequently analysed and compared by the first author and then aggregated into an overall analysis. The interpretations in the overall analysis were verified within the international research team. Due to the general vulnerability of our sample and the complex international context of our study, we did not undertake a member check of our findings.

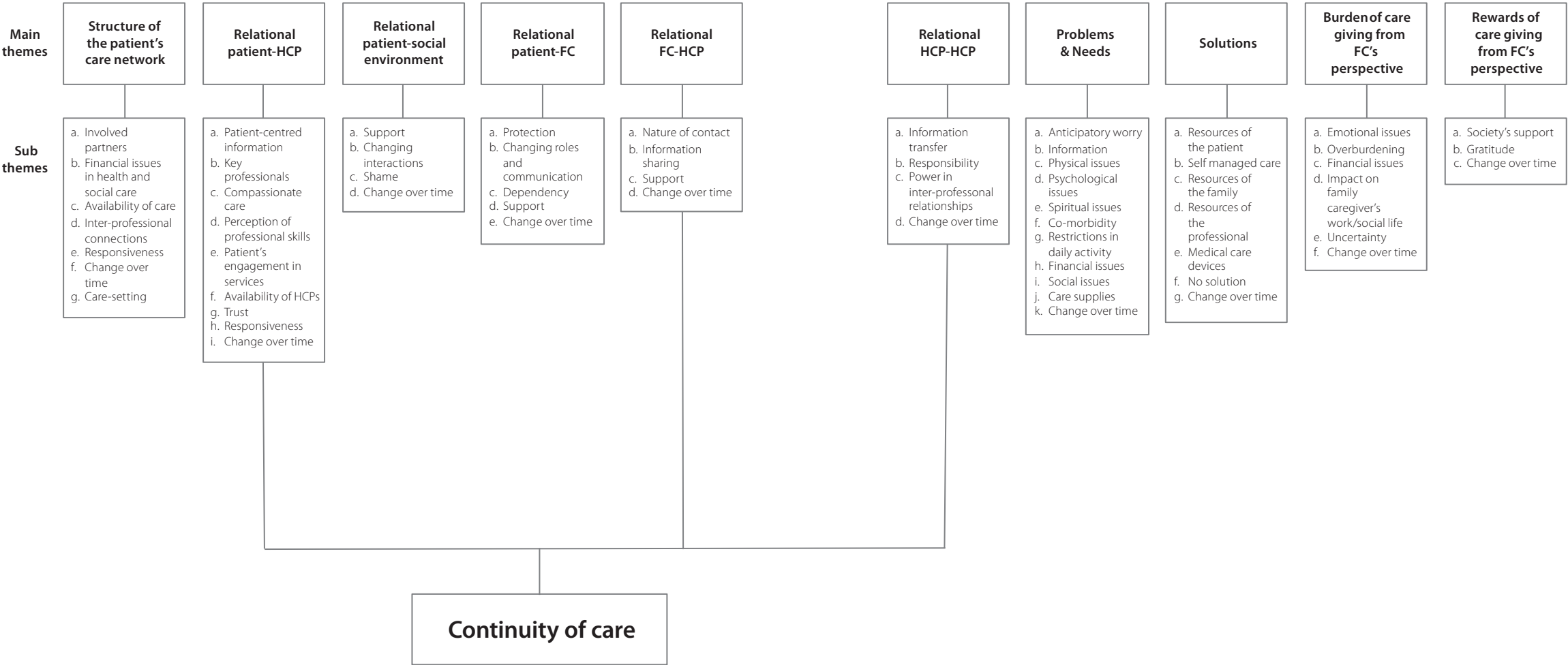


Figure 1 International codebook.

We used the consolidated criteria for reporting qualitative studies (COREQ) checklist³⁹ as far as this was applicable to our study.

Results

A total of 22 integrated palliative care initiatives were included mainly involving hospital- or hospice-based services in conjunction with home care services (Table 3). In all, 152 patients

participated in the study: 15 in Belgium, 34 in Germany, 37 in Hungary, 31 in the Netherlands and 35 in the United Kingdom. The mean age was 68 years, the majority were female (56%) and had cancer (63%). Most patients had their partner (59%) as family caregiver. The majority of patients (62%) also took part in the second interview. A total of 92 family caregivers participated in the interviews, 15 in Belgium, 16 in Germany, 26 in Hungary, 22 in the Netherlands and 13 in the United Kingdom. The mean age was 61 years old and the majority were female (66%). Just over half of the family caregivers (54%) also took part in the second interview, due to loss to follow-up (Table 4).

Table 3 Integrated Palliative Care initiatives recruited.

Initiative ID (country + initiative number)	Type of initiative	Diagnostic groups served (COPD/Heart failure/ Cancer)
BE1	Specialized palliative home care service	All, mainly cancer
BE2	Home care nursing service	All
BE3	Specialized palliative home care service	All, mainly cancer
G1	Hospital based palliative care service in conjunction with primary and secondary care	All, mainly cancer
G2	Hospital based palliative care service in conjunction with primary and secondary care	All, mainly cancer
G3	Hospital based palliative care service in conjunction with primary and secondary care	All, mainly cancer
G4	Hospital based palliative care service in conjunction with primary and secondary care	All, mainly cancer
HUN1	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
HUN2	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
HUN3	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
HUN4	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
HUN5	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
NL1	Hospital based Heart failure team in conjunction with primary care	Heart Failure
NL2	Hospital based COPD nursing and rehabilitation ward	COPD
NL3	Hospital based multidisciplinary oncology service in conjunction with primary care	Cancer
NL4	Palliative home care service	All, mainly cancer
NL5	Hospital based palliative care service in conjunction with primary care	All, mainly cancer
UK1	Hospice based service in conjunction with primary and secondary care	All
UK2	Hospice at home service in conjunction with primary and secondary care	All
UK3	Hospice based service in conjunction with primary and secondary care	All
UK4	Nursing home service	All
UK5	Hospice based service in conjunction with primary and secondary care	All

COPD: chronic obstructive pulmonary disease.

Table 4 Respondent characteristics by country.

	Belgium	Germany	Hungary	Netherlands	United Kingdom	Total
Patients (N)	15	34	37	31	35	152
Age, years (N, SD)	69 (12)	69 (12)	68 (9)	70 (8)	66 (12)	68 (10)
Gender (N, %)						
female	8 (53)	18 (53)	23 (62)	14 (45)	22 (63)	85 (56)
male	7 (47)	16 (47)	14 (38)	17 (55)	13 (37)	67 (44)
Diagnosis (N, %)						
Cancer	12 (80)	31 (92)	13 (35)	22 (71)	18 (51)	96 (63)
COPD	3 (20)	3 (9)	15 (41)	6 (19)	10 (29)	37 (24)
CHF	-	-	9 (24)	3 (10)	7 (20)	19 (13)
Number of patients who participated in the second interview (N, %)	8 (53)	13 (38)	22 (59)	23 (74)	28 (80)	94 (62)
Family caregivers (N)	15	16	26	22	13	92
Age family caregivers,^a years (mean, SD)	65 (12)	60 (14)	56 (16)	62 (11)	63 (13)	61 (14)
Gender FCs (N, %)						
female	7 (47)	10 (63)	21 (81)	15 (68)	8 (62)	61 (66)
male	8 (53)	6 (38)	5 (19)	7 (32)	5 (39)	31 (34)
Number of FCs who participated in the second interview (N, %)	6 (40)	10 (63)	12 (46)	15 (68)	7 (54)	50 (54)
Family caregiver relation to patient?^a (N, %)						
(un)married partner	12 (86)	20 (67)	15 (41)	19 (68)	17 (52)	83 (59)
parent	-	-	1 (3)	-	2 (6)	3 (2)
child	2 (14)	8 (27)	12 (32)	4 (14)	8 (24)	34 (24)
other	-	2 (7)	9 (24)	5 (18)	6 (18)	22 (16)

SD: standard deviation; COPD: chronic obstructive pulmonary disease; CHF: congestive heart failure.

^aThis question is about patients' family caregivers in general thus includes more family caregivers than only those who participated in the interviews.**Relational continuity**

Relational continuity appeared prominent in all countries. Both positive and negative experiences related to having or not having close relationships with a small number of health care professionals (e.g. hospital specialists, general practitioners (GPs), nurses,

physiotherapists or hospice care professionals) and seeing them on a regular basis. These health care professionals paid attention to the person behind the illness and took time to talk about respondents' personal lives, rather than only about the illness. It provided trust when respondents were known to health care professionals, so that these could take their needs and wishes into account to tailor care:

Well, he promised me to die in a decent way. What she meant by that, I am not sure [...]. But she has promised: 'You can count on me'. (B1P3, cancer)

Also, these health care professionals were always available and responded adequately in case of needs, as perceived by respondents:

I call my carers [hospice staff] if I need and I get immediate help. They are available all day and night, my GP also gave me his private phone number. (HU2P2, COPD)

Furthermore, continuing relationships with certain health care professionals enabled monitoring of the patient's illness progress: *'They actually know each other very well. In the way he is sitting [the heart failure nurse] can see how he is' (NL1C1, heart failure)*. For a number of respondents in Belgium and the Netherlands, this monitoring function was the reason that they wanted to continue their relationship with their oncologist.

However, lack of relational continuity was often experienced as well and meant that respondents needed to spend a lot of energy in building new relationships, reiterating their histories and that they did not know what they could expect from health care professionals:

[...] it's hard because, you know, really you should be building a rapport up with the GP [so that] when you are ill he comes out, he knows you, you're not convincing him. But the one that I have been going to for years is leaving now as well. (UK2P4, cancer)

More specifically, experiences of relational continuity with GPs varied widely across countries. Many respondents highly valued longstanding relationships with their GPs and GPs' comprehensive knowledge of them: *'And then I talked to him [GP], because he knows me for a long time' (G2P12, COPD)*. Also, GPs often had an important role in coordinating care, prescribing medication and making referrals. However, at the same time many respondents in all countries, but predominantly in Hungary, Germany and the United Kingdom, experienced a lack of involvement of their GPs:

Our GP didn't come at all. He [the patient] is at home since September, but the doctor didn't visit him ... When we need something, for example tube or catheter, I've to spend hours making phone calls. (HU4C1, cancer)

Many GPs seemed to take the backseat when patients were (still) treated by hospital specialists, or specialized palliative care teams. Consequences were that respondents did not receive the support they needed and/or expected from their GPs.

Informational continuity

Respondents found it very important that health care professionals were well informed as they felt it prevented them from repeating their histories and provided trust that health care professionals had the right information to make correct treatment decisions:

If you all know the same things then you've a better quality of treatment and more chance of success. (UK3P1, COPD)

However, in all countries informational continuity seemed to be a weak point in care provision. This was revealed in situations in which many different health care professionals were involved, within the hospital, between hospital specialists and GPs, between hospitals and during acute (out-of-hour) situations. At these moments, it became apparent that health care professionals were often badly informed about the patient's history, did not have access to other health care professionals' patient records or did not have regular contact:

My impression is that they [hospital physicians] do not always read the record accurately, and that they do not know the whole thing about me. (G2P4, cancer)

The GP, since half a year I think, he receives a little letter about what was done. [...] I had been with the oncologist for two years. [...] I was being treated and I was coming back twice a month to make a photo or CT-scan. The GP didn't know anything ... So I'm visiting the GP one time for another little thing and: 'Cancer?' he says. I say: 'Yes, cancer'. (NL5P2, cancer)

Negative consequences resulting from this according to respondents included the need to reiterate medical histories several times, receiving contradictory information, worries about the quality of care and becoming agent of information transfer between health care professionals, while many respondents did not want to have this responsibility:

P: [...] the GP prescribed antibiotics. Then we went to the hospital day clinic [...]: 'oh no, she cannot take these antibiotics with her liver'. And then we had to contact the GP and tell the GP what the hospital had said ... those things! (B1P1, cancer)

[...] So you need to take control while you actually want to give it away. (NL3C2, cancer)

In contrary to the abovementioned, in all countries respondents provided examples of health care professionals who worked closely together in teams or networks and were often well informed about respondents' medical histories and personal circumstances. Respondents appreciated that they did not have to ensure information transfer between health care professionals anymore. Interestingly, we observed that these health care professionals were often involved in collaborative integrated palliative care initiatives:

There is a close relationship between them [hospice team], daily contact ... All professionals share the information with others. (HU4P1, cancer)

Yes, they are in constant touch. That's why I don't have to explain the medication to the qualified palliative physicians ... (G3C2, cancer)

I think [the network works together] now a lot more because everything's on the computer [...] when I go to my GP, you don't have to have the letter with you that's come from the hospital ... (UK5P1, cancer)

Management continuity

Respondents wanted to be seen as a person with multidimensional needs rather than a medical subject. This required that health care professionals viewed respondents with a holistic lens and provided multidisciplinary care in order to support their multidimensional needs:

I understand that doctors at the Pulmonology [department] treat my lungs, but I also have constriction of the arteries in my legs ... (HU4P9, heart failure)

I: What do you think about all these different persons who are dealing with this [illness]? FC: Well, I think that is [...] very good. It cannot be done by one single person. That seems nearly impossible. [...] I do assume that there are all kind of connections [between HCPs] going up and down. I do perceive this as well. (NL5C6, cancer)

The importance of this became clear with several examples provided by respondents in which multidisciplinary care was absent or obstructed. Many respondents experienced that health care professionals worked in a fragmented fashion and only dealt with their own medical specialty. We found this fragmented care mainly among individual hospital specialists and between hospital specialists and GPs. Consequences for respondents were that problems were inadequately addressed, remained unaddressed or were discovered too late:

[GP and oncologist] ... sometimes, they think only inside their box. [...] The GP has been looking on his computer for 20 minutes which antibiotics he could give [...] He should be able to just grab his phone and say: 'listen I have that patient, that medical file number, she has these symptoms, what can I give?' ... (B1C1, cancer)

[About missed diagnosis of broken leg]: ... he [urologist] kept persisting that he wasn't able to see anything on the screen. [...]. But, [...] if he is not able to see it, he could have passed that on to another physician like: 'this madam complained a little about her leg'. Then he could have send her [patient] to Orthopaedics. Then we would have been much further and earlier than [now] that we had to stay with him having done nothing about it. (NL5C9, cancer)

In contrast, several respondents clearly perceived the differences when multidisciplinary care was provided:

... the advantage of [care networks] being connected is that you get the optimum care [...] Now that I've had lots of referrals and I've been able to access some exercise, a dietician, hospice workers to help with my will or thinking about a funeral, psychology to help me and to give me advice ... (UK5P8, heart failure)

Respondents often did not know how health care professionals exactly worked together and many were not particularly interested in this, as long as they received multidisciplinary care. However, in all countries some respondents appreciated that health care professionals formed small collaborative groups in which they consulted each other and provided referrals to other health care professionals. For example, a number of respondents in Germany, the Netherlands, Belgium and the United Kingdom knew that health care professionals came together in meetings, resulting in impressions that care was connected and coherent. These collaborative groups often seemed relevant for health care professionals involved in integrated palliative care initiatives:

I know that they have like a big ... a big meeting about my Mam's care [...] I'm sure it's like [Breast Care Nurse Specialist], the Oncologist, and it might even have been [the Bone Specialist] as well. (UK2C3, cancer)

... with those [palliative care and radiology] I have the feeling that it all fits together like cogwheels. (NL5P2, cancer)

Discussion

This article examined how relational, informational and management continuity of care are experienced by patients with advanced cancer, COPD or heart failure and family caregivers receiving care from several integrated palliative care initiatives in five European countries. Concerning relational continuity, respondents found it very important to have trusted relationships with a small number of key health care professionals in order to receive tailored care and easily access help when needed. GPs had an essential role for many respondents across the five countries, because of their established relationships with patients. However, as multiple health care professionals were involved in order to meet respondents' needs, relational continuity was often at stake. This was especially the case with GPs who appeared to take the backseat when hospital/palliative care specialists were involved. As a result, patients and family caregivers felt abandoned by their GPs and sometimes lacked the support they needed.

Thus, although adequately supporting multidimensional needs of patients with advanced illnesses and family caregivers requires multidisciplinary care⁴⁰, it can jeopardize relational continuity. Such impact of structure and organization of services on the involvement of valued key health care professionals and experiences of patients has been described elsewhere²⁷. These findings highlight the need of patients and family caregivers to maintain relational continuity, especially when multiple health care professionals are involved. Our results suggest that in order to maintain relational continuity, multidisciplinary collaboration could be enacted by health care professionals behind the scenes, but at service level respondents may only need a small number of key health care professionals who are readily available without exactly knowing how health care professionals collaborate. Additionally, GPs need to be more involved in multidisciplinary care provision for patients with advanced illnesses. Both hospital/palliative care specialists and GPs should take that responsibility.

Furthermore, our findings demonstrated that although patients and family caregivers needed and expected to receive multidisciplinary collaboration, informational and management continuity were still¹¹ a weak link in care provision. Many health care professionals seemed to lack a collaborative attitude in which they focus on the needs of patients and family caregivers and work closely together with other health care professionals by consultation and information transfer. As a result, many patients and family caregivers did not find adequate support for their needs and were burdened with information transfer between health care professionals. This is in line with the study of Seamark et al.¹⁰ who found that information transfer between primary and secondary care often does not take place, according to experiences of bereaved caregivers in the United Kingdom. Moreover, Richardson et al.¹¹ showed that even if consultation and referral does take place between multidisciplinary teams, it is not clear who is responsible for treatment; this could still disrupt and delay care.

In contrast, similarly to findings from previous studies^{24, 34}, we found that where collaborative initiatives between health care professionals existed, multidisciplinary care and information transfer did take place and patients and family caregivers felt that care provision was connected and coherent. Respondents in our study often referred to health care professionals involved in integrated palliative care initiatives. Thus, integrated palliative care initiatives that particularly focus on the needs of patients and family caregivers and use a person-centred collective team approach can have an important role in improving informational and management continuity. However, our study additionally suggests that as informational and management continuity was deficient despite the existence of collaborative integrated palliative care initiatives, fuller integration of these initiatives with other health care professionals is necessary to optimize continuity of care.

Strengths and limitations

The international context of the study enabled collection of rich data. However, data collection and analysis were done by different researchers in each country with a potential risk of methodological inconsistencies. We have limited these as much as possible using uniform interview protocols and training on data collection and analysis, regular support via Skype and face-to-face meetings and electronic correspondence to reflect on findings and prevent inconsistencies. Furthermore, in order to limit the likelihood of interpretation bias for the cross-country comparison, the data were peer reviewed with the researchers in each country in order to ensure correct interpretations. We aimed for theoretical sampling with the aim of attaining a balanced sample of patients with cancer, COPD or heart failure in all five countries and to compare experiences for patients with different diseases. However, in practice it appeared challenging to recruit the intended sample, especially for patients with COPD and congestive heart failure (CHF) as these are in the minority within integrated palliative care initiatives.

Some aspects seemed to be more an issue in some countries than in others, such as the role of the GP. However, a nuanced interpretation of these international data is difficult to achieve and requires understanding of the particular country context, including health care system and funding mechanisms. Notwithstanding, we found many common aspects that contributed to continuity of care suggesting that health care professionals and policy makers across countries can learn from each other in finding successful solutions for improving continuity of care experiences.

Conclusion

This international qualitative study showed that patients and family caregivers are most likely to experience continuity of care by having a small number of health care professionals who are available, who provide multidisciplinary care and who regularly transfer

information to all health care professionals involved. Collaborative integrated palliative care initiatives could optimize continuity of care experiences and thus improve quality of palliative care in Europe. However, further integration of these initiatives with other health care professionals involved in the care networks of patients with advanced diseases and their family caregivers is needed. Researchers, clinicians and policy makers could use these insights in order to enhance integrated palliative care and improve experiences of patients with life-threatening diseases and family caregivers.

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5

Patient and family caregiver perspectives on their participation in palliative care

a qualitative study

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Submitted

Abstract

Objective

Most patient participation studies focus on the patient-physician dyad which may neglect the interdisciplinary context of palliative care and the role of family caregivers (FCs). This study aims to identify, from the perspectives of patients and FCs, how participation of patients and FCs is shaped in palliative care trajectories.

Methods

Qualitative analysis.

Results

Thirty-one Dutch patients (mean age 70 years, predominantly male, 71% advanced cancer) and 22 FCs (mean age 62 years, predominantly female) participated. Seven forms of participation were identified. Patients and FCs differed in their preference and ability to influence participation. Healthcare professionals did not always offer the opportunity for patients and FCs to participate. A person-centred attitude of healthcare professionals and a collaborative and assertive attitude of patients and FCs facilitated participation.

Conclusion

It is crucial to coordinate participation so that it meets the patient's and FC's needs and wishes and is possible within the specific clinical circumstances. Participation should be made explicit early in the palliative care trajectory and based on a dialogue, whereby healthcare professionals, patients and FCs have joint responsibilities.

Practice implications

This study can guide future research and educational programs to enhance participation, if needed, to improve clinical practice.

Introduction

In current healthcare systems, providing patient-centred care has become increasingly important¹. One of the cornerstones to achieve this is active patient participation¹. Patient participation means that decisions about the content, planning and organisation of the patient's care trajectory are based on a dialogue between the patient and the healthcare professionals (HCPs)^{2, 3}. It acknowledges patients' autonomy as well as their values and wishes, and recognises the knowledge and expertise of both the HCPs and the patient³⁻⁵. Although participation and shared decision making are often used interchangeably⁶, participation has the broader meaning of involving patients in each step of the care trajectory, not just making decisions about medical treatment³. Patient participation improves satisfaction with healthcare and helps patients feeling more informed^{3, 7}. Notwithstanding its acknowledged importance and benefits in healthcare, in current clinical practice patient participation is often limited⁸ or is not congruent with patients' expectations⁹. Moreover, patients not only differ in the extent to which they wish to participate in their care trajectory, they are also not equally capable to do so⁹⁻¹¹.

Therefore, how to achieve effective patient participation and which knowledge, skills and attitudes⁸ are needed for HCPs, patients and family caregivers (FCs) are still subjects of research. Haidet et al.¹² showed that individual patients adopt various strategies to shape their care trajectory depending on their illness narratives. Hudon et al.¹³ suggested family physicians to have a role in guiding patients through their care trajectory, e.g. by acknowledging patients' knowledge and capacities. These studies were conducted in primary care and involve patients with chronic illnesses in general.

For patients in a palliative care (PC) trajectory participation may be even more challenging and they may have different values and preferences compared to patients in a curative trajectory¹⁴. Bergdahl et al.¹⁵ and Bélanger et al.¹⁰ have focused on patient participation in the specific context of PC. Bergdahl et al. demonstrated how joint treatment goals are co-created between nurses, palliative patients and FCs. Similarly, Bélanger et al. observed how patient participation is constructed by both patients and PC professionals during outpatient and ambulatory consultations.

These studies provide useful evidence of the complex process of patient participation and how it is constructed within the context of PC. However, most studies on patient participation in PC focus on the patient-physician dyad¹¹. This may neglect the interdisciplinary context of PC and the important role of FCs¹⁶. Relationships between patients, FCs and other HCPs may also influence the extent to which patients participate to shape their care trajectory. This study aims to investigate how participation of patients and FCs takes shape in PC trajectories.

Methods

Design

This study involves a secondary analysis¹⁷ of interviews held in the Netherlands as part of a larger qualitative study in five European countries about the experiences of seriously ill patients and FCs with integrated PC¹⁸. The original study specifically focused on the perceived quality and continuity of care¹⁸. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist¹⁹ was used to report our findings.

Recruitment

Patients and FCs were recruited from five preselected integrated PC initiatives in the Netherlands as part of InSup-C, a larger European Seventh Framework Programme project about integrated PC (inclusion criteria for the initiatives have been published elsewhere)¹⁸. HCPs involved in these initiatives selected eligible respondents based on inclusion criteria (Table 1) and informed them about the study. If respondents expressed interest in participation they received further information and the request to fill in a consent form.

Table 1 Inclusion criteria for patients and FCs.

General criteria
1. 18 years or above
2. Able to communicate in the Dutch language
3. Cognitively able to participate in interviews
Specific patient criteria
1. The patient's attending doctor answers "No" to the surprise question: "Would you be surprised if the patient died within 1 year?"
2. Any of the following diagnoses:
A) Advanced cancer (cancer with local progression and / or distant metastasis at presentation)
B) Severe heart failure in accordance with NYHA classification stage III-IV
C) COPD Gold stage IV classification

Data collection

After obtaining written consent, patients and FCs participated in two semi-structured interviews. The interviews focused on how HCPs responded to patients' needs and included three parts: 1) problems and needs of the patient, 2) relationships with HCPs in the patient's care network and 3) collaboration between HCPs. For FCs we additionally explored their own relationships with HCPs.

The first two patient interviews were regarded as a pilot study. Since analysis revealed no need to change the content of the interview guide, these interviews were included in the final sample. Interviews were mainly conducted at home and took one hour on average. Data were collected between June 2014 and August 2015. Interviews were audio-recorded and transcribed verbatim.

The study did not fall within the remit of the Dutch Medical Research Involving Human Subjects Act (WMO) and was therefore waived for further review by an ethics committee (Medical Research Ethics Committee Arnhem-Nijmegen, The Netherlands 2013/538).

Data analysis

Interview data were analysed using qualitative content analysis²⁰. Two researchers (MG, MH) inductively coded five patient and/or FC interviews separately using line-by-line coding. Then line-by-line codes were discussed and clustered into larger codes. Larger codes were discussed with the other members of the research team and when necessary adjusted and refined accordingly, resulting in a codebook. Subsequently, the first author coded all interviews using this codebook. Newly emerging codes were added to the codebook until no new codes emerged anymore. The first author identified main themes from the codebook and discussed these with the other members of the research team. Quotes were added to illustrate each theme. Qualitative Data Software Nvivo 10 was used in order to support the coding process.

Results

Respondent characteristics

Thirty-one Dutch patients with a mean age of 70 of whom the majority were male and had cancer participated in this study (Table 2). Also, twenty-two FCs with a mean age of 62, predominantly female, participated. In most cases, the FC was the patients' partner.

Seven forms of participation were identified from patients' and FCs' perspectives. These varied from the patient, FCs or HCP taking a leading role, to partnerships between either the patient, FC and /or HCP.

One person takes the lead

The patient takes the lead

A number of patients had clear expectations about their treatment and how they wanted to shape their own care trajectory. They proactively discussed their wishes and treatment preferences with HCPs. (NL3P6: [doctor]: "How are you going to do that?" [patient]: "Well, the way they solve it here [hospital] is by performing enemas; I can do that myself at home. So, I can

Table 2 Respondent characteristics.

Patients (N)	31
Age, years (mean, SD)	70 (8)
Gender (N, %)	
Female	14 (45)
Male	17 (55)
Diagnosis (N, %)	
Cancer	22 (71)
COPD	6 (19)
CHF	3 (10)
Number of patients who participated in the second interview (N, %)	23 (74)
Family caregivers (N)	22
Age family caregivers, years (mean, SD)	62 (11)
Gender family caregivers (N, %)	
Female	15 (68)
Male	7 (32)
Number of family caregivers who participated in the second interview (N, %)	15 (68)
Family caregiver's relation to patient? ^a (N, %)	
(Un)married partner	19 (68)
Parent	–
Child	4 (14)
Other	5 (18)

SD: standard deviation; COPD: chronic obstructive pulmonary disease; CHF: congestive heart failure
^aThis question is about patients' family caregivers in general, thus includes more family caregivers than only those who participated in the interviews.

now do that myself." [...] [doctor] "Well, if you can do it yourself, that's fine with me, then I'll stick to managing the process.")

According to patients, HCPs sometimes just needed to follow the patients' own ideas. (NL4P3: *I said to the pulmonologist: "Well, listen", because I'd already seen a scan before, "I don't want to be treated [...].but I'd like to hear from you, if I do these two awful tests, will you give me an honest answer, no matter how terrible the results are? And, please, confirm it, otherwise I won't do it."*).

Some patients were given a leading role by their HCPs because they were made responsible for making a decision about follow-up or further treatment. However, one respondent reported that she did not feel that she was able to bear this responsibility. (NL5P9: *My previous GP said like, "Shall I visit every week?"[...] But this new GP says, nicely, if I want something, "Just call me. Then we'll discuss what we'll do on the phone." So I never go for a consultation. [...] You think about that sometimes [...] How's my disease going to develop? [...] Will he come then, or will I need to call him and say, "Well, today I'm not feeling well, could you visit?" Then you think, "How long can I put that off?" And maybe by putting it off too long, I'll have made the wrong decision."[...] So, what will happen when I'm almost dead. Should I call and say, "Doctor, I'm almost dead."[...] What will he say then? Well, I'll just have to wait and see."*)

Another respondent provided a similar example, referring to the oncologist. (NL3C7: *"So, now they want to return to the chemo from when [patient] just got this intestinal cancer. Well, we don't have very good memories of that [...] So, well, we're not looking forward to that at all; like would it be a good idea?" [...] We went home yesterday and the [oncologist] said, "Well, just see what you want to do; here's the name of the chemo, have a look on the Internet." So, well, there you are then.*)

The HCP takes the lead

Some respondents had a hierarchical view of HCPs, especially medical specialists. They completely trusted the professional's knowledge and skills, without realising that they could also discuss their own wishes. Thus, they let the HCPs take a leading role (NL3P1: *You're under supervision and you completely depend on the cardiologist. So, whatever he does, you simply assume that it's the right thing.*)

In other cases, HCPs took the lead in a way that was not congruent with respondent's wishes. (NL3P7: *"He [oncologist] just wants to palm another chemotherapy off on me"*). A number of HCPs were described as being disease-focused rather than person-focused, and only being open to the treatment option that was best in their opinion, without respecting the preferences of the patient (NL5C2: *She's [oncologist] too busy with that organ there, and it feels like other things... I don't know, don't really seem to interest her [...], and she doesn't really show any respect for that.*) and (NL5P2: *you can be good friends with [oncologist], if you just pander to her wishes*).

Such disease-focused behaviour also stimulated patients who seemed acquiescent to become assertive by confronting HCPs with the way they led the care trajectory. [The urologist discovered the patient's broken leg resulting from metastases too late. The patient's view was that he didn't look at any issues not directly related to her tumour]: NL5P9: *Yes, he [urologist] actually saw that it wasn't OK too late. [Later] I said to this professor, "You listened to what I said,... but you didn't really listen." And I really noticed that.*

The FC takes the lead

Some FCs were highly involved with, and sometimes even paternalistic towards, the patient. (NL3C2: *A day when we have appointments consists of trying to spread these across the day. [...] A full programme is impossible for her, because of her extreme tiredness. [...] Shopping, or things like that, I do that; I think that's normal, because I think that it's all too much for her, which is not necessary. So I believe you can prolong life, in this case my partner's, by relieving her from as much as possible, both mentally and physically.*)

Sometimes FCs even told HCPs how to provide care (NL1C1: *And I didn't like what they [the home care] were doing, so they changed everything a little bit towards what I wanted; it's good that they [home care workers] really take what I want into account.*)

Although HCPs collaborated with both the patient and FC because of their attitude (NL3C2: *And what I like is that the oncologist tells us, "I can't do it on my own, we'll in this together"*), in one case the FC's strong leading role resulted in a reactive HCP. This was, however, not what the FC wanted (NL3C2: *She [Oncologist] asked, "When did we start the hormone therapy?" I thought, "That's really too much!" [...] I said, "I'll check it for you, dear." So I checked my records and, because I work with week numbers and dates, I told her, "I'll check my book" because I have a lot of records of course. "It was in week 3 on this date and at that time." [...] Then you really get angry, don't you?! "When did we start the hormone therapy?" Good grief, it's unbelievable!*)

A partnership between either the patient, FC and/or HCP

The patient and HCP form a partnership

Some patients described having a partnership with HCPs (NL5P8: *That kind of collaboration [with PC doctor and PC nurse], that cheers me up. Then you're already a team of three.*) An assertive and collaborative attitude of patients enabled collaboration with HCPs. (NL5P10: *You build your own relationships with [HCPs]. [...] By... adopting a certain attitude, you ... build up a relationship. So that [...] they know who I am, they know what I want. Also... you often see that, ...like, "We [HCPs] know that you don't want that", and of course that has been discussed when I said: "I'm going to stop chemotherapy". Then they [HCPs] take that into account, there's no nagging, they don't try to talk me round. No, my choice is respected.*)

HCPs can also provide an environment that either encourages or discourages partnerships. (NL5P5: *...the way [pain specialist and physiotherapist] treat you, that... [...] they treat you like an equal. And well, the [urologist] tends to act a bit superior. But the guy from the pain clinic... he's not very good using the computer and we have great fun with that; we can have a laugh and, I think, "He's almost human, every now and then".*)

A number of respondents described HCPs who were person-centred because they listened well and focused on personal circumstances, showing that patients' input mattered: (NL5P9: *We experienced [the first PC team consultation] [...] like a home-coming. [...]*)

We were simply amazed; "Wow, what about that - someone's really listening." They also ... listened to our feelings, took our home situation and needs into account.)

Others mentioned HCPs who involved them as a partner by showing and explaining the oncologist's test results (NL5P2: *...actually only when I was given PC did I see the photos of my back and, well, the last time, those of my lungs as well [...]; I'd never been shown them by [the oncologist]*) and by discussing treatment possibilities in relation to the wishes of the patient: NL5P12: [interviewer]: *How was your first contact [with PC]? [patient]: Well, I was asked, "What can I do for you?" [...] [interviewer]: and how did you experience that conversation? [patient]: Quite open, [...] it gave us more insights into and knowledge about [pain] treatment options than what we'd known till then about severing those small nerves.*

The patient, HCP and FC form a combined partnership

In many cases, a partnership between both patient and FC with the HCP was described: (NL5P9: *Well, that is really a collaboration between the PC team and my husband, who is there as well, and myself as a kind of central figure. Currently, that's the way it works.*)

This was because in most cases, patients and FCs formed a close dyad that visited consultations and made healthcare decisions together. (NL3C1: *Well actually, I have the same relationships with [HCPs] as you [patient] do, haven't I? We do everything together.*)

Person-centred HCPs enabled FCs to be actually involved in the care trajectory. (NL5C7: *And... what I found important, or find, is that it's not only the patient, but that I'm involved as well. In many things. [...] they ask how I am. [...]. I always say, I'm fine, but I do have my own worries as well.*) Although a number of FCs appreciated their involvement in the care trajectory, others remained more in the background and found that the patient was central. (NL5C8: *... I wouldn't know what the PC team would need to say to me, because I think, well, "I'm not important." Not for them; I'm only important for [patient].*)

The patient and FC form a partnership

A number of FCs and patients had a self-caring attitude, and waited before seeking help from HCPs or family for as long as possible. (NL5C9: *And as a matter of fact we never wanted to bother anyone, because we can arrange everything ourselves; [...] we're self-supporting.*) Some of them accepted the involvement of HCPs in their PC trajectory only when the HCPs themselves identified urgent needs of the patient and FC: NL5P9: *And [PC professionals] also noticed what we needed at home. It simply couldn't go on like that anymore. I was alone. I needed help. And they saw that. Until that moment a partnership with HCPs seemed not possible.*

The FC and HCP form a partnership

In some cases FCs and HCPs formed a partnership: (NL2C5: *[Home care workers] work together with me as well. When something happens, they call me.*) However, in one case the

patient seemed to be too much in the background in the partnership between HCPs and FCs (NL5P8: ...the last time [case manager] wasn't there [at the consultation] [...]. Usually, my eldest daughter and [FC] are there with me. And then I need to be very alert, and I often don't have the energy for that, [to ensure] that it's about me, not about them. [...] [Oldest daughter] sometimes has a couple of questions, which she asks [...] and then I'm sitting there with three or four people but I feel I'm just sitting there for the show. [...] Then I badly missed [case manager] because he's there for me as well.)

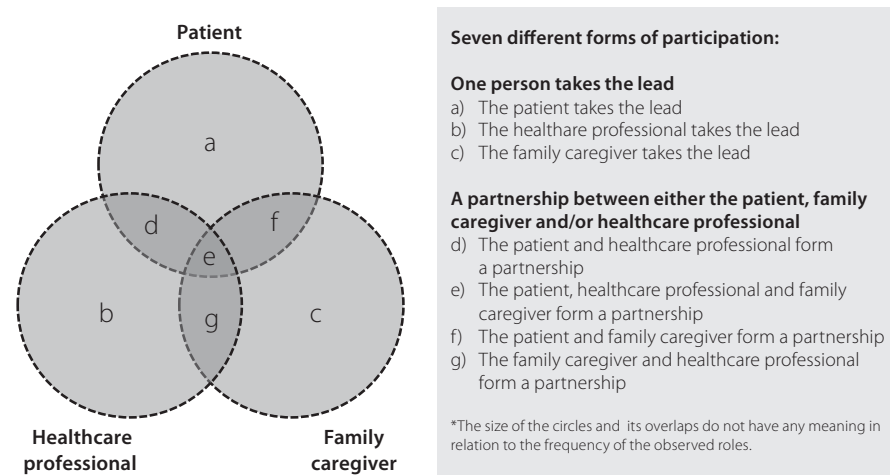


Figure 1 Seven forms of participation of patients and FCs in PC trajectories.

Figure 1 displays the seven identified forms of participation from the perspectives of patients and FCs. Individual patients and FCs shaped participation in different ways and their roles were dynamic over time as well.

Discussion and conclusion

Discussion

This study identified seven forms of patient's and FC's participation from the perspectives of patients and FCs in PC trajectories. These varied from one person taking a leading role to partnerships between either the patient, FC, and/or HCP. Other studies also described that the roles of patients and FCs and the way they participate throughout the care trajectory are dynamic over time^{10, 12}. Roles depend on the attitudes individual patients, FCs and HCPs adopt during their relationship¹⁰ and on care experiences and illness backgrounds¹² of patients and FCs.

Nowadays, patients are expected to be an active partner of HCPs to shape their care trajectory⁵. However, patients have unique participation preferences depending on their illness narrative¹² and the stage of the illness²¹. Therefore, there is no uniform way of participation, or ideal model to shape the care trajectory²². More important seems that the extent of participation and the way patients and FCs participate is congruent with their wishes. This study confirms^{9, 11} that this is not always the case. Expectations patients or FCs had about participation sometimes conflicted with the reality of clinical practice. Ensuring that participation is congruent with patient's and FC's wishes is the responsibility of HCPs, patients and FCs². Therefore, it is important that patients, FCs and HCPs are aware of their roles and that they have the possibility to adjust these depending on their preferences and the care situation.

This study suggests that at the one hand HCPs do not always offer the opportunity for patients and FCs to participate actively. Possibly, because HCPs are not always aware of their responsibility to involve patients in discussing treatment options or do not know how to do this^{23, 24}. At the other hand, patients and FCs in this study differed in their ability to influence participation. Some patients or FCs were assertive and shaped their care trajectory in a way they preferred. Other patients or FCs adapted their role to the attitudes and behaviour of their HCPs, but seemed not satisfied with this. Moreover, the stage of the illness also defines the ability of the patient to participate^{21, 25}. Furthermore, while many studies focus on the patient-physician dyad¹¹, Washington²⁶ also included FCs in their analysis of interdisciplinary team meetings. They found that FCs were not always involved in decision making in a meaningful way. Since FCs often have a significant role in the quality and coordination of the patient's PC trajectory^{16, 27}, it is essential to also enable their participation. In some instances in our study however, FCs had a dominant role potentially limiting the patient's participation. This role is problematic if it is not congruent with the preferences of the patient.

These results suggest that it is crucial to coordinate participation in such a way that it meets the needs and wishes of patients and FCs and is possible in the specific clinical circumstances at the same time. The patient's illness or clinical circumstances may limit the possibilities to take wishes of the patient and or FC into account. E.g., when patients are in such a serious illness phase that only limited treatment options are left. This complex context emphasizes that participation should be based on a dialogue or sometimes negotiation process between HCPs, patients^{2, 10} and FCs throughout the PC trajectory. This dialogue should be made explicit early in the illness trajectory to enable changing participation.

HCPs have a pivotal role to facilitate a dialogue and make it explicit early in the illness trajectory. Therefore, it is essential that they adopt a proactive and person-centred attitude

towards patients and their FCs². General practice nurses in Desborough et al.'s study²⁸ did this by starting building rapport and taking time to know patients' unique needs. In our study, HCPs (predominantly PC professionals and a number of individual HCPs) adopted a person-centred approach by listening carefully to patient's personal wishes and circumstances, providing transparent information, discussing treatment options, explaining the collaboration and treating the patient as equal. These elements have been found in other studies as well^{2, 3, 21}. Additionally, tools have been identified to support HCPs in promoting patient's participation in healthcare decisions²⁹.

Knowing the appropriate behaviour² and the required mix of abovementioned elements to achieve the desired patient participation depends on the individual patient, FC and the particular moment in time^{21, 30}. Therefore, HCPs need to develop craftsmanship to be "aware enough to recognize the preferred style of the patient [and FC] and adaptive enough to respond accordingly"².

Also patients and FCs have a responsibility to ensure that this dialogue is successful. In this study, patients or FCs enabled participation by adopting a collaborative attitude and making their preferences about treatment decisions and expectations about the organisation of care explicit. Other studies highlighted that empowerment strategies such as being informed, asking questions and improving communication skills may enhance patients' level of participation as well^{3, 30, 31}. Especially in the PC trajectory in which much is uncertain not only for patients and their FCs, but also for HCPs¹⁰, enabling a dialogue to take place in a successful way is essential.

Strengths and limitations

This study provides insight in different forms of patient's and FC's participation in PC trajectories. This insight may help patients, FCs, and HCPs to become aware of the role(s) they adopt during their encounters and adjust these if needed. Although we achieved thematic saturation, this study included a relatively small sample of predominantly patients with advanced cancer. The perspectives of patients with non-cancer diagnoses or other backgrounds (e.g. patients with a small care or social network) who are in a PC trajectory may be underrepresented. Since this study was based on a secondary analysis, some questions remained unanswered, such as whether additional forms of participation existed. These may include other family members, such as sons or daughters, or interdisciplinary meetings that are attended by patients and/or FCs.

Furthermore, this study only included the perspectives of patients and FCs. Future research should focus on the perceptions of HCPs of their collaboration with patients and FCs. The forms of participation identified in this study should be further validated. Future research could focus on validating the forms of participation and examine whether an

awareness raising intervention including these forms can improve perceived participation of patients with PC needs.

Conclusion

This study identified seven forms of patient's and FC's participation in PC trajectories. Patients, FCs and HCPs have the joint responsibility to ensure that participation is congruent with the wishes of patients and FCs within the possibilities of the specific clinical circumstances. Not all patients with PC needs and FCs are capable to bear this responsibility. HCPs have a pivotal role to facilitate a dialogue by making it explicit early in the illness trajectory. Patients and FCs can enhance participation by adopting a collaborative attitude and making their preferences about treatment decisions and expectations about the organisation of their care explicit.

Practice implications

This study can guide future research and educational programs to increase patients', FCs' and HCPs' awareness of how they collaborate and how they can enhance participation, if needed, in order to improve clinical practice.

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6

Towards accessible integrated palliative care:

Perspectives of leaders from seven European countries on facilitators, barriers and recommendations for improvement

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Abstract

Purpose

Literature suggests that integrated palliative care (IPC) increases the quality of care for palliative patients at lower costs. However, knowledge on models encompassing all integration levels for successfully implementing IPC is scarce. This paper aims to describe the experiences of IPC leaders in seven European countries regarding core elements, facilitators and barriers of IPC implementation and provides recommendations for future policy and practice.

Design/methodology

A qualitative interview study was conducted between December 2013 and May 2014. In total, 34 IPC leaders in primary and secondary palliative care or public health in Belgium, Germany, Hungary, Ireland, the Netherlands, Spain and the UK were interviewed. Transcripts were analysed using thematic data analysis.

Findings

IPC implementation efforts involved a multidisciplinary team approach and cross-sectional coordination. Informal professional relationships, basic medical education and general awareness were regarded as facilitators of IPC. Identified barriers included lack of knowledge about when to start palliative care, lack of collaboration and financial structures. Recommendations for improvement included access, patient-centeredness, coordination and cooperation, financing and ICT-systems.

Originality/Value

Although IPC is becoming more common, action has been uneven at different levels. IPC implementation largely remains provisional and informal due to the lack of standardised treatment pathways, legal frameworks and financial incentives to support multilevel integration. In order to make IPC more accessible, palliative care education as well as legal and financial support within national healthcare systems needs to be enhanced.

Introduction

Palliative care aims to prevent and alleviate suffering of patients with life-threatening diseases and their families by early identifying and treating their multidimensional symptoms¹. Several studies have shown that palliative care is effective in terms of quality of life and costs²⁻⁵. However, as problems of accessibility and care fragmentation persist, an integrated care paradigm is increasingly being applied to optimise the quality of palliative care provision⁶⁻⁹. Integrated care seeks to improve quality of care for patients by ensuring that care is well coordinated around their needs¹⁰. It involves various structures and processes that should be pursued at several care levels in order to achieve comprehensive service delivery, addressing individual patient and population needs^{11, 12}.

Although integrated palliative care (IPC) lacks a single, commonly agreed definition, a starting point is provided in various sources. For example, the World Health Organization¹³ states among others that palliative care should be provided through person-centred and multidisciplinary care. Furthermore, studies demonstrating the effectiveness of palliative care integration incorporate specific palliative care components (e.g. routine screening, assessment and support of multidimensional symptoms, advance care plans and a multidisciplinary team approach) into standard care for patients with life-threatening diseases²⁻⁵. Additionally, several models and indicators to promote IPC are being developed, but these need further evaluation^{8, 9}. Despite these references to integrated care in a palliative care context, knowledge on models encompassing all integration levels and preconditions for successfully implementing IPC in both oncology and non-oncology is scarce and requires further investigation¹⁴⁻¹⁶.

The European research project (InSup-C) aims to fill this gap by investigating best and promising IPC practices for patients with cancer, Chronic Obstructive Pulmonary Disease (COPD) and Chronic Heart Failure (CHF) in Europe in order to identify requirements for IPC. In the absence of an IPC definition InSup-C proposed a working definition (Box 1) and published a taxonomy of IPC¹⁷. A predominant part of InSup-C was an international embedded case study examining several promising IPC initiatives¹⁸. In preparation for this study, qualitative interviews with leaders in the field of IPC were conducted. This paper describes the findings of these interviews, focussing on barriers and facilitators experienced during IPC implementation and recommendations to make IPC more accessible.

Box 1 InSup-C’s working definition on IPC

Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers (paid and unpaid).

Methods

Recruitment and sampling

This study used a qualitative interview design which allows for obtaining in-depth insight into how IPC is currently implemented and what factors challenge or promote implementation in InSup-C partner countries. Leaders in the field of IPC in InSup-C partner countries (Belgium, Germany, Hungary, the Netherlands, Spain and the UK) were purposively recruited. Although Ireland was not an InSup-C partner country, one experienced leader that could provide useful insight on IPC implementation in the field of COPD was included. For recruitment each InSup-C consortium member was requested to identify “national leaders” in the realm of IPC. Additionally, letters were sent to boards of national associations of cancer, heart and lung diseases asking for potential leaders in the integration of palliative care in their respective fields. Participants needed to fulfil the following inclusion criteria: knowledge and experience in palliative care and/or public health in cancer and/or non-cancer, working on a minimum degree of local palliative care integration, professional background as physician, nurse, social worker, caregiver, researcher, or patient organisation representative and English communication skills.

A preliminary list included 53 interview candidates. Snowballing during data collection extended the sample to 59 participants. Candidates received an invitation letter explaining the scope of the InSup-C project and the aim of the interview. In total, 34 participants accepted the invitation (eight from the UK, six from Germany, six from the Netherlands, six from Spain, four from Hungary, three from Belgium and one from Ireland; Table 1). Two participants accepted the invitation but no date for the interview could be found. In total, 17 participants did not respond to the invitation letter; six participants rejected the invitation. Although we realise that these numbers are not balanced across countries and therefore not sufficient to achieve saturation in terms of regional themes, the interviews provided saturation in terms of shared elements of IPC practices, barriers and facilitators.

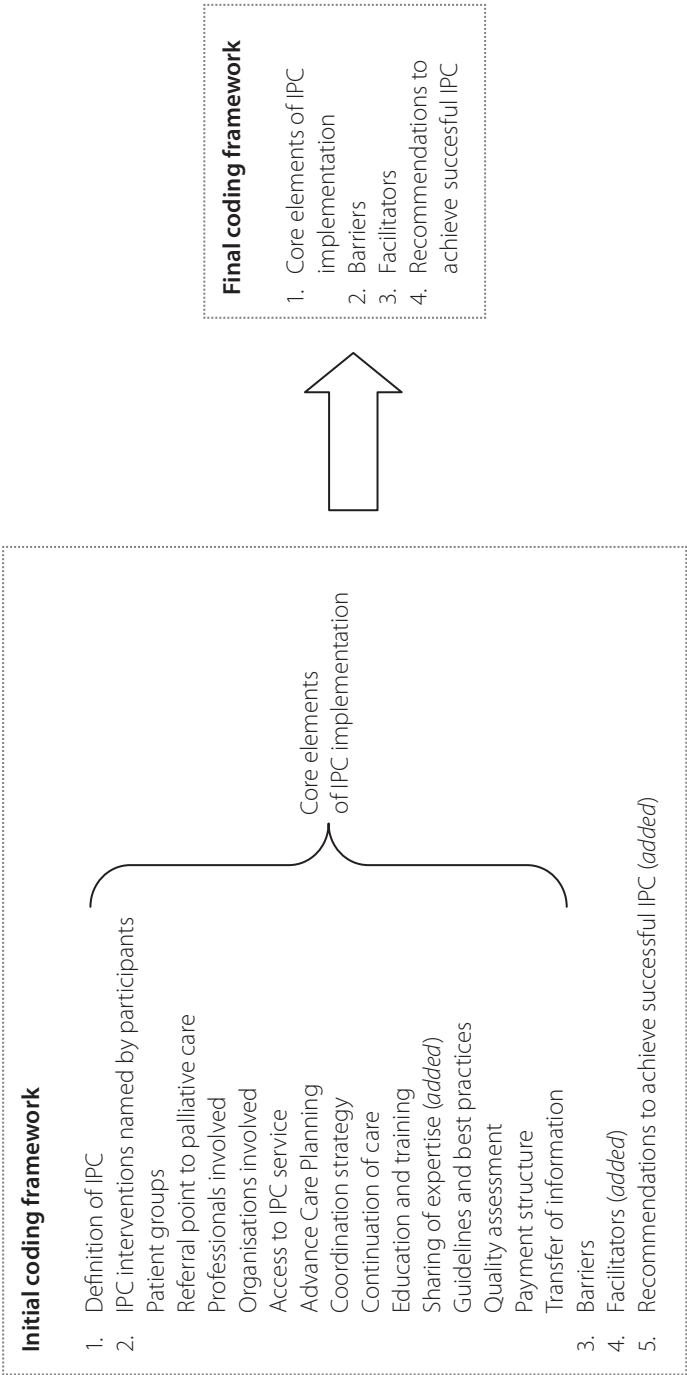


Figure 1 Initial and final coding framework.

Data collection

Semi-structured interviews were conducted using an interview guideline focusing on the process behind IPC interventions and covering five key dimensions:

1. Definition of IPC.
2. IPC interventions in the participant's country and beyond based on the IPC working definition.
3. If interventions named: description of the intervention for which the participant could provide most detailed information. If no interventions named: how is palliative care integrated in the work setting?
4. Threats and obstacles with implementation.
5. Characteristics for a successful patient-centred model for IPC.

As patients were not included in the study, approval from a research ethics committee was 225 not required. All experts provided their verbal consent before being interviewed. The interviews were conducted face-to-face (12 interviews) and via Skype (22 interviews) depending on participants' preferences and logistics. Interview duration averaged 42 minutes. Interviews were audio taped and transcribed verbatim.

Analysis

Transcripts were analysed using thematic data analysis¹⁹ allowing identification of themes in advance while being flexible to add new themes emerging from the interview data. Transcripts were first coded using a coding framework that was based on the interview guideline. Two researchers coded the first five interviews together. The remaining interviews were coded separately. Results were compared and discussed, resulting in three additional codes ("Sharing of expertise", "Facilitators" and "Recommendations to achieve successful IPC"). As four categories predominated, the final coding framework included four key categories (core elements of IPC practices, barriers, facilitators, recommendations to achieve successful IPC). Figure 1 shows the initial and final coding framework. Quotes were selected in order to illustrate the findings. Data analysis software programme Nvivo 10 was used to support the analysis. The consolidated criteria for reporting qualitative studies (COREQ) checklist²⁰ were used as far as this was applicable to this study.

Results

Table 1 presents participant characteristics of which the majority were male. Professional backgrounds were diverse with a majority of physicians with different specialities. The four key categories are described in the following section.

Table 1 Participant characteristics.

	N
Gender	
Male	22
Female	12
Professional background	
Physicians	24
Health care researcher	3
Nurses	3
Physiotherapists	2
Clinical psychologist	1
Mental-health counsellor	1
Country of origin	
UK	8
Germany	6
Netherlands	6
Spain	6
Hungary	4
Belgium	3
Ireland	1

Core elements of IPC implementation

IPC implementation mainly involved a multidisciplinary team approach including links between hospitals and home care services or sometimes hospices. Palliative care specialists often had an advisory function to support professionals who had basic palliative care training. In some cases palliative care physicians had a more active treating role. At a clinical level a large variety of patient groups was targeted, including patients with malignant and non-malignant diseases (e.g. COPD, CHF, neurologic illnesses). However, at places where IPC was provided for all disease types the majority of patients were affected by cancer. Points of referrals to palliative care differed considerably according to participants. Mechanisms for identification and referral of patients with palliative care needs to palliative care services were not incorporated into standardised treatment pathways, but were rather formed during multidisciplinary meetings (MDTs) where clinical judgment had an important role. Coordination of care was often not standardised in treatment pathways either, although most initiatives made use of professionals fulfilling a key worker role and MDTs to coordinate care. MDTs were not only a means for coordination and communication among professionals, but also had a networking and educational function. Overall, information was mainly transferred through informal communication

channels, such as regular phone calls. Many participants used an electronic patient record, but these were often setting-bound or only accessible by the IPC team. Only two participants reported making use of an electronic patient record that was widely accessible across the region or network.

Facilitators

Facilitators to implementation of IPC focussed on creating awareness about palliative care's added value and building expertise. In particular, this included the importance of informal professional relationships, basic medical education and general awareness. Above all, participants described how informal relationships between departments and professionals facilitated small-scale multidisciplinary collaborations: "[...] there was a good basis on which we worked together and because it was lots of joint working and lots of cooperation between existing services the oncology team and the lung specialists and this new care service" (UK No. 5; physiotherapist working in outpatient palliative care).

These collaborations, in turn, facilitated dissemination of palliative care expertise: "because we work closely with the local hospice the advanced care practitioner there and the consultant in the hospice they are very good at using the opportunity for feedback also as a learning opportunity" (IR No. 1; nurse working in hospital).

At a professional level, participants found that professionals and particularly non-cancer specialists (e.g. surgeons, pulmonologists, cardiologists) have increasingly accepted palliative care involvement: "I think, you know, in the last ten years I feel shift in that and it is probably likely to continue" (UK No. 3; palliative care consultant working in a hospice). In many of the interviews participants related this growing acceptance to increased basic education in terms of palliative knowledge and skills: "[...] mainly in education. This degree on subspecialty and the other about obligatory trainings for young physicians it's a big, big result. I am very happy with this and perhaps it's a step to the integrated palliative care" (HU No. 4; mental-health counsellor working in a hospice).

In addition to growing professional awareness, some participants felt that there was greater recognition of the importance of IPC from key stakeholders, including professional associations and insurance companies. This was resulting in increased interest, new legislation and greater funding for palliative care: "[...] we had in 2002 the law of palliative care with, well funded, government made enough [provided] money for palliative care in Belgium" (BE No. 1; palliative care specialist working in a hospital and teaching at university).

Barriers

Although IPC is growing in importance, participants experienced a series of barriers when trying to implement IPC in practice. These related to a lack of knowledge about when to start palliative care, lack of collaboration and lack of appropriate financial structures.

Many participants experienced late palliative care integration with inappropriate referrals related to insufficient knowledge about when to start palliative care and healthcare

systems' focus on curative treatment. Despite growing awareness of palliative care, many people felt that it is still often used as a synonym for the care of terminally ill cancer patients, especially in the field of non-cancer: "I mean, healthcare professionals continue with some kind of expectations about palliative care. That means that palliative care patients are patients that are going to die in a short period of time. [...] You know, in the last days [...] in [the] end of life. And this vision continues" (ES No. 4; palliative care physician working in a hospital). Interviews also revealed that, especially in hospital settings, death is still a taboo, complicating access to palliative care.

Despite the increased willingness to collaborate, participants felt that fragmentation, traditional silo-based ways of working and lack of structures for professional integration (e.g. lack of formalised meetings and non-standardised procedures for information transfer between sectors and team members) made collaboration difficult: "And finally there has been a push for multidisciplinary working for patients with severe heart failure, which is on their mind. [However], I'm not sure that happens well in clinical care, I think conceptually people accept this, but I think putting that into practice in a clinically workable form I think it's quite difficult" (UK No. 7; cardiologist working in a hospital).

Also at system level, participants met various challenges from financial structures hindering IPC implementation: "Especially, sectorial fragmentation and coexisting financial structures prevent an integration of palliative care into the regular system of service provision" (GER No. 5; oncologist working in a hospital).

Resources were also not always sufficient to ensure IPC access for all patients in need of palliative care. These were not just financial, but could also include lack of skilled staff and lack of time. Lack of finances affected the number of beds in hospices, but also resources needed to enable multidisciplinary care provision: "Our healthcare system is very much affected by the recession. So a lot of our patients could live at home. But there isn't the social service available for people that don't have primary carers that are capable of looking after them" (IR No. 1; nurse working in hospital).

Recommendations for improvement

Participants identified considerable potential to improve IPC implementation in order to make it more accessible. Recommendations included improving IPC accessibility for non-cancer groups, increasing patient-centeredness in care organisation, enhancing multidisciplinary collaboration and providing financial support.

Many participants expressed the wish to upscale IPC implementation to non-cancer patients. A number of them perceived that IPC is often related to diagnosis or prognosis and therefore excludes many (particularly non-cancer) patients. Participants recommended a shift towards needs-based approaches: "They work best and palliative care works best when it is not restricted by a specific diagnosis. So [instead of] the cancer-non-cancer I guess just the progressive illness or advanced progressive illness because that embraces the sort of specialties views of a person-centred care and needs-based intervention it

shouldn't be about someone's diagnosis specifically" (UK No. 7; cardiologist working in a hospital).

This also required health systems to shift from exclusive end of life care to inclusive and widely accessible palliative care: "[...] we have got to become much more flexible in our models of integrating ourselves with other services and reduce our kind of hospice-centred profile of 'coming to the hospice and we'll take care of you until you die' approach, which is really an unsustainable model, it's a Rolls Royce service for a few patients, but what we really [got to] get out there is a, is a Mercedes Benz for everybody" (UK No. 8; physician working in a hospice). For some participants, greater accessibility also implied the need for an increased number of beds on palliative care wards and hospices.

At the clinical level, a number of participants identified the need for increased patient-centredness in order to improve care organisation: "I think that the patient has to be in the middle and we all work around him" (ES No. 6; geriatrician working in hospital). Suggestions to enhance patient-centredness included increased patient involvement in the decision process and more patient contact (e.g. through more consultation time and, according to one participant, more bedside consultations).

At a professional level, many participants found that persisting routines of professionals working in isolation with palliative care as only a final stage needed to be broken up. They recommended establishing new routines in which multidisciplinary teamwork and care coordination were standard practices. Following from this recommendation, many participants suggested enhancing palliative care education and some recommended improved guidance on recognition of needs and triggers for referral: "[...] what we also need for integrated palliative care is maybe some more guidelines and [...] standardised procedures is maybe a little bit too strong, but some kind of a guiding through how to treat patients in palliative care and I think, well, another thing we need, is, is making physicians more aware of when you start palliative care [...]" (BE No. 2; geriatric and palliative care physician working in hospital).

For a number of participants this raised the need to implement IT systems that can improve information exchange and thus enable multidisciplinary care: "We should do a kind of more with telecommunication, with computers, that once a week you make a little meeting with telecommunication, maybe with the patients included, to see if everybody is happy, to see ideas, to ask the question if the palliative care specialist has to come or another caregiver, so maybe that would be a good step" (NL No. 6; cardiologist working in an outpatient clinic at hospital).

Finally, this required financial support at system level: "In my opinion, integrated palliative care, as it is discussed internationally, requires a well-orchestrated cooperation of healthcare institutions and organisations, caregivers and – last but not least – also funding agencies" (GER No. 5; oncologist working in a hospital).

Discussion

IPC implementation in this study mostly takes place on an informal and small-scale basis. It is mainly realised because of palliative caregivers' networking capacities, facilitated by policies on raising awareness among physicians and populations which has resulted in increased acceptance and support. However, barriers at clinical, organisational and financial level keep IPC practices at an early stage of development instead of achieving accessible IPC systems at larger scale. Participants recommend that patient-centred, needs-based approaches, integrated (financial and organisational) structures and clinical guidance are required at all healthcare levels to achieve IPC implementation.

Valentijn et al.¹¹ have developed a conceptual framework useful for understanding the complexity of integrated care. They distinguish integration at several levels that complement each other: system integration at macro level; networking, organisational and professional integration at meso level and clinical integration at micro level. Functional and normative integration link all integration levels together. Valentijn et al.¹¹ emphasise that integration should take place at all levels across the health system in order to achieve integration and person-centred care. Applying Valentijn et al.'s¹¹ conceptual framework of integrated care to the study results suggests that access to IPC has developed unevenly at different levels. Most strikingly, the extent of integration achieved in the perception of participants seems to gradually diminish from micro to macro level. IPC has most likely succeeded at the level of clinical integration (micro level) where MDTs stimulate (early) referral of patients with palliative care needs and coordination functions have been employed in order to ensure continuity of care. At the meso level, professional and organisational integration have been achieved to an extent, with professionals establishing informal networks enabling key features of integration such as multidisciplinary treatment which transcends organisational boundaries. However, if such approaches towards integration are not carefully nurtured (or are non-standardised or even non-existent), professionals (e.g. GPs, medical specialists and palliative care specialists) and healthcare providers (e.g. outpatient services, hospice and hospitals) can have difficulties with integration. System integration (macro level) is seen as a key mechanism for upscaling IPC but, so far, is considered mostly incomplete by participants. Many of them found that further IPC implementation not only requires increased education, but also administrative reforms ensuring sustainable financing and organisation of IPC. This study's findings suggest that current IPC implementation efforts remain rather provisional and fragmented due to the structural shortcomings of different healthcare systems.

Barriers and facilitators described in this study are similar to the existing literature in the field of palliative care in general²¹⁻²⁴, demonstrating the international importance of these themes. However, this study particularly focussed on what barriers and facilitators

participants face when actually implementing IPC. The results confirm that in order to promote IPC, integration should take place at several levels of care instead of only adding palliative care as a new specialist silo to standard care at one level. This insight can be used to guide the development of new models of IPC¹⁷, improving existing models of integrated cancer care^{8,9}.

Strengths and limitations

This study's strength is its international scope with a sample of 34 participants from seven European countries providing rich data. The results highlight that solutions to implementing IPC may not be limited to national boundaries. A major limitation of the study is its small sample reducing its generalisability. For this reason, underlying factors enabling or disabling IPC implementation at a regional level could not be explored in-depth. Although the consistency of our results with other studies supports the validity of the findings, further research with an additional sample of IPC leaders may be helpful to confirm our findings. As a result, another InSup-C study by Centeno et al.²⁵ investigated leaders' opinions on barriers and opportunities to the integration of palliative care according to levels of service provision across Europe. Notwithstanding these limitations, this study is a good starting point for further in-depth investigation of IPC. As a next step, a multiple embedded case study with 23 promising IPC initiatives in five European countries was conducted in order to examine IPC implementation in-depth and identify elements for successful IPC integration²⁶. A publication of this study is forthcoming.

The predomination of the sample by physicians may have biased our results, meaning that IPC practices with non-medical elements (e.g. integration of palliative care and social care) were possibly underrepresented. Notwithstanding this, the physicians in our sample came from various backgrounds including both oncologists and non-oncologists, allowing us to show that barriers and facilitators towards IPC implementation were not unique for cancer.

Conclusion

This study suggests that IPC implementation is taking place at several levels of integration. However, IPC implementation efforts remain provisional and informal due to insufficient palliative care knowledge and a lack of standardised treatment pathways, legal frameworks and financial incentives to support multilevel integration. Therefore, the extent to which IPC is realised or not seems to depend too much on professionals' discretionary engagement and available local resources. In order to manage the leap from local IPC implementation efforts to accessible IPC services at larger scale, education as well as legal and financial support within national healthcare systems need to be enhanced.

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7

Integrated palliative care is about professional networking rather than standardisation of care:

a qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries

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Abstract

Background

Integrated palliative care aims at improving coordination of palliative care services around patients' anticipated needs. However, international comparisons of how integrated palliative care is implemented across four key domains of integrated care (content of care, patient flow, information logistics and availability of (human) resources and material) are lacking.

Aim

To examine how integrated palliative care takes shape in practice across abovementioned key domains within several integrated palliative care initiatives in Europe.

Design

Qualitative group interview design.

Setting/participants

A total of 19 group interviews were conducted (2 in Belgium, 4 in the Netherlands, 4 in the United Kingdom, 4 in Germany and 5 in Hungary) with 142 healthcare professionals from several integrated palliative care initiatives in five European countries. The majority were nurses (n=66; 46%) and physicians (n=50; 35%).

Results

The dominant strategy for fostering integrated palliative care is building core teams of palliative care specialists and extended professional networks based on personal relationships, shared norms, values and mutual trust, rather than developing standardised information exchange and referral pathways. Providing integrated palliative care with healthcare professionals in the wider professional community appears difficult, as a shared proactive multidisciplinary palliative care approach is lacking, and healthcare professionals often do not know palliative care professionals or services.

Conclusion

Achieving better palliative care integration into regular healthcare and convincing the wider professional community is a difficult task that will take time and effort. Enhancing standardisation of palliative care into education, referral pathways and guidelines and standardised information exchange may be necessary. External authority (policy makers, insurance companies and professional bodies) may be needed to support integrated palliative care practices across settings.

What is already known about the topic?

- Although integrated palliative care aims at improving coordination of palliative care services around patients' anticipated needs, there is limited evidence about which integrated palliative care models could lead to optimal palliative care.
- In order to promote integrated care, four key domains of the care delivery process need to be well organised (content of care, patient flow, information logistics and availability of (human) resources and material).
- Palliative care literature describes these key domains only to a limited extent, for example, by referring to studies on the development of referral criteria to promote early integration as well as by the identification of indicators and elements important for palliative care integration into oncology and chronic care.

What this paper adds?

- This paper suggests that the dominant strategy for fostering integrated palliative care is building core teams of palliative care specialists and extended professional networks, rather than developing standardised information exchange and referral pathways.
- Although this seems a strength, integration still remains fragile due to its informal nature based on mutual trust and sharing values as well as its limited scope.
- Therefore, integrated palliative care provision beyond extended professional networks, where healthcare professionals do not share a proactive multidisciplinary palliative care approach and do not know palliative care professionals, is jeopardised

Implications for practice, theory or policy

- In order to promote better integration in regular healthcare, convincing the wider community is needed, but this is a difficult task that will take time and effort.
- Standardisation of palliative care into education, referral pathways, protocols and guidelines and standardised information exchange may need to be enhanced.
- Building evidence for the importance of delivering high-quality palliative care together with influence from external authorities, such as policy makers, insurance companies and professional bodies may be needed.

Introduction

Fragmentation of healthcare services and late referrals to palliative care prevent many patients from receiving the palliative care they need at the right time and in the right place^{1, 2}. Therefore, many patients have unmet palliative care needs³, experience undesired hospital admissions in the last weeks of life⁴ or are not able to die at their preferred place⁵. Several studies have suggested that integrated palliative care (IPC) leads to better results in terms of quality of life, costs and even survival⁶⁻⁸. IPC aims at improving coordination of palliative care around patients' anticipated needs^{9, 10} and can be defined as: 'bringing together administrative, organisational, clinical and service aspects of palliative care in order to achieve continuity of care between all actors involved in the care network of patients receiving palliative care'¹⁰.

However, IPC is not easily achieved. Roles and responsibilities of generalist (professionals who are primary responsible for the patient) and specialist palliative care professionals are not always clear^{11, 12}. Moreover, some generalist professionals fear that they find themselves taking the backseat in the care of their patients^{11, 12}. Other challenges include lack of clarity about the level of expertise needed for palliative care and uncertain illness trajectories (especially regarding non-cancer diagnoses) that make it difficult to know the best timing to involve palliative care professionals^{11, 12}. There is limited evidence from palliative care literature about which IPC models could lead to optimal palliative care¹³. For this reason, it may be useful to turn to the growing body of evidence of integrated care in chronic illnesses. An extensive body of literature in integrated chronic care¹⁴⁻¹⁶ is available suggesting that in order to promote integrated care, four key domains of the care delivery process need to be well organised: (1) content of care – ensuring that patients receive the right care, (2) patient flow – ensuring that the right patients receive care at the right time from the right healthcare professional (HCP), (3) information logistics – ensuring that the right information is available at the right time and (4) availability of (human) resources and material – ensuring that the right HCP and the right medication and equipment are available at the right time.

Current palliative care literature describes some aspects of the abovementioned key domains. For example, patient flow was investigated in studies which developed referral criteria to promote early palliative care integration^{17, 18}. Hui et al.¹⁹ described aspects of content of care by identifying indicators for the integration of palliative care in oncology (i.e. interdisciplinary teamwork, routine symptom screening, advance care planning and educational activities). Siouta et al.²⁰ found similar results in their review of empirically tested IPC models in cancer and chronic diseases. However, literature^{21, 22} also suggests that availability of (human) resources is often insufficient to enable widespread integration of palliative care. Although these studies could contribute to promoting IPC, international

comparisons of how IPC is implemented across these four domains are lacking. Therefore, this article focuses on how IPC takes shape in practice across the four key domains of integrated care within several IPC initiatives in five European countries.

Methods

This study used a qualitative group interview design. Group interviews enable participants to interact and complement each other's answers. Therefore, compared to individual interviews, group interviews can provide a broader spectrum of data including various insights in a particular phenomenon²³.

Recruitment

This study was part of a multiple embedded case study conducted by the European InSup-C project that aimed to identify prerequisites for successful IPC²⁴. A total of 23 IPC initiatives were selected based on inclusion criteria described elsewhere²⁴. In order to select participants for the group interviews, we requested contact persons of the initiatives to indicate HCPs that were part of the initiative. In order to include outsider perspectives as well, invitation lists also included HCPs who cared for patients receiving care from the initiative but were not directly involved in the initiative. Therefore, we asked patients who had been recruited from the initiatives for an interview study²⁴ for their consent to contact HCPs in their care networks for participation in a group interview. Invitation lists included a large number of HCPs per initiative (range: 15–25) in order to achieve a number of 6–10 participants per group interview. Participants were invited by e-mail.

Data collection

Group interviews were conducted using a semi-structured interview protocol. The interview protocol was based on the four predefined key domains (content of care, patient flow, information logistics and availability of (human) resources and material) and included open and probing questions. A preliminary interview protocol was discussed and approved within the international research team and was pilot tested in the United Kingdom and in Germany. Findings from the two pilots were discussed within the international research team resulting in a final interview protocol (Appendix 3). This procedure ensured a uniform group interview procedure across countries, irrespective of language or culture group. Participants provided verbal consent before starting each group interview. Group interviews lasted on average of 90 min (range: 1–2 h) were mainly held at the initiatives' locations and were facilitated and observed by two researchers from each national research team with experience in qualitative research and/or palliative care. Group interviews were audio-recorded and transcribed verbatim. Data were collected between May 2015 and January 2016.

Review committee approvals were obtained in all participating countries²⁵. In the Netherlands, the study did not fall within the remit of the Medical Research Involving Human Subjects Act and was therefore waived for further screening by the ethics committee.

Data analysis

In order to enable uniform analysis of international data, the Dutch research team analysed the group interview transcripts from all countries. Transcripts that were not written in Dutch or English were translated into English by professional translators. Group interview transcripts were analysed using a deductive content analysis approach²⁶. This approach allowed us to examine how IPC takes shape in practice by building on already existing theory on integrated chronic care.

First, three researchers from the Dutch research team read all group interviews in order to become familiar with the data. In order to provide the Dutch research team with the required contextual knowledge to draw accurate interpretations from the international data, face-to-face and Skype discussions were held with national research teams in order to clarify health systems characteristics and particular national topics. Subsequently, one researcher deductively analysed the group interviews using the four key domains from the interview protocol as sensitising concepts to identify relevant themes. Identified themes were discussed within the Dutch research team until consensus was reached. In order to check validity of the themes and interpretations, these were peer reviewed by the international research team.

The analysis was supported by qualitative data software ATLAS.ti 7.1. Due to the complex international context, the authors anticipated it would be difficult to organise a member check with the original group interview participants. Therefore, we did not include a member check. However, the Dutch team frequently consulted the national research teams during international project team meetings. To report on the data collection and analysis methods, we used the consolidated criteria for reporting qualitative research (COREQ) checklist²⁷.

Results

A total of 19 group interviews were conducted: 2 in Belgium, 4 in the Netherlands, 4 in the United Kingdom, 4 in Germany and 5 in Hungary. Four initiatives did not participate due to lack of time or inability to further cooperate in the study. Initiatives involved specialised or general palliative care services based at various settings (home, hospital, hospice and nursing home; Table 1). Although all initiatives aimed to provide IPC for patients with both cancer and chronic diseases, the majority of patients had cancer. In total, 142 participants attended the group interviews of which the majority were nurses (n = 66; 46%) and physicians (n = 50; 35%; Table 2). Other participants included an occupational therapist,

pharmacists, physiotherapists, psychologists, social workers and spiritual caregivers. Themes we identified for each of the four key domains are presented in Table 3.

Content of care

Ensuring that patients receive the right care is based on whether HCPs share a proactive multidisciplinary palliative care approach. This approach includes anticipatory holistic assessment of patient's current and future needs and wishes as well as multidisciplinary collaboration between all professionals involved in the patient's care:

[...] you try to think anticipatory [...]: 'Well, we've got this scenario, we can expect that and this has consequences for care provision' [...] You try to integrate this element [of] 'multidisciplinary anticipatory thinking'. (NL4)

Most initiatives seem to consist of a core team, an extended professional network (hereafter extended network) and a wider professional community (hereafter wider community; Figure 1). The core team generally consists of HCPs who share a proactive multidisciplinary palliative care approach. Core team members meet each other regularly, for example, during multidisciplinary meetings (MDTs), discuss patients' multidimensional needs and make joint care plans:

At onco-team meetings we discuss the patients' further treatments and care. In my opinion, it works very well for us. (Pulmonologist 2: HU1)

HCPs from the core team have strong informal ties with HCPs in the extended network who also share a proactive multidisciplinary palliative care approach but are not actively involved in the core team. Although HCPs in the extended network meet core team members less frequently, they report good collaboration for providing IPC:

As a family doctor [...] I feel even more integrated, even though I am not always here at the [multidisciplinary team] discussions. [...] I experience it as a positive togetherness that since [integrated palliative care initiative] started, as far as I can recall, there haven't been any patients who were taken to hospital for a short period of time and died, but everything happened at home in absolute peace and with really perfect organisation. (G2)

However, participants report difficulties providing IPC when it concerns HCPs in the wider community. *We are here together with [...] a selected group of [palliative care] people [...]. There are, well, many colleagues whom I think are poorer with regard to providing [palliative] care. (NL3).* HCPs in the wider community seem not to share a proactive multidisciplinary palliative care approach but often adopt a culture focussing on the medical and curative aspects of care. Participants therefore report insufficient collaboration with HCPs in the

Table 1 Characteristics of integrated palliative care initiatives in the study.

Type of initiative ^a	Setting in which initiative was originated				Diagnostic groups served in initiative (COPD/Heart failure/Cancer)	Initiative IDs (Country + Initiative number)	Example of an integrated palliative care initiative in this category
	Home	Hospital	Hospice	Nursing home			
Specialised palliative care support service	X				All, mainly cancer	B1, B3	Secondary specialised palliative team providing consultation and palliative home care on request to regional hospitals, palliative care units, regional nursing homes, home care and replacement home environments.
Specialised palliative care service in conjunction with specialised palliative home care services and/or other primary and secondary care services		X			All, mainly cancer	G1, G2, G3, G4, NL5, HU1	Collaboration between specialised palliative care unit at (academic) hospital and specialised palliative home care team providing palliative care at home and coordinating several services in the community.
Specialised palliative care service in conjunction with primary and secondary care			X		All, mainly cancer	UK1, UK3, UK5 HU4	Collaboration between inpatient hospice providing day therapy and several services in the community such as hospitals, GP practice, nursing services, ambulance services, nursing/residential care homes.
General palliative care service in conjunction with specialised palliative care (support) service	X				All, mainly cancer	B2, UK2 NL4, HU2, HU3	General home care service providing palliative care at home with the support of a regional specialist palliative care team.
General palliative care nursing home service in conjunction with secondary care		X		X	COPD	NL2	Inpatient COPD nursing and rehabilitation ward located at a regional hospital providing palliative care and preparing patients to live at home.
General palliative care service in conjunction with primary care		X			All, mainly cancer	NL3, HU5	Multidisciplinary oncology unit at a regional hospital collaborating with specialised palliative care case managers who coordinate palliative care in the community.

COPD: chronic obstructive pulmonary disease; GP: general practitioner.
^a Specialised means that the majority of healthcare professionals involved in the initiatives are palliative care specialists, while general means that of the healthcare professionals involved in the initiative, only a few are palliative care specialist or have received basic palliative care training.

Table 2 Participants who attended group interviews.

Profession	N
Nurse ^a	66
Physician ^b	50
Physiotherapist	6
Psychologist	6
Social worker	6
Spiritual caregiver	4
Pharmacist	2
Occupational Therapist	1
Other	1
Total	142

COPD: chronic obstructive pulmonary disease; GP: general practitioner.
^a Mainly includes home care nurses, specialised nurses or nurse specialists in, for example, COPD, heart failure, oncology and palliative care.
^b Mainly includes GPs, palliative care specialists and some cardiologists, pulmonologists, internists, pain specialists and geriatricians.

Table 3 Key domains and corresponding themes.

Key domains	Themes
Content of care	Sharing a proactive multidisciplinary care approach within the core team, extended professional network and wider professional community
Patient flow	The influence of available palliative care knowledge and informal professional relationships on palliative care referrals and hospital discharges
Information logistics	Variations in quality of information transfer and standardisation within core team, extended professional network and wider professional community
Availability of (human) resources and material	Solutions for availability of trained staff and medication during out-of-hours

wider community, resulting in a lack of continuity of care:

And so that's our biggest challenge, [...] that all of us – and that means across all of the different health settings – all have to take a responsibility to work together. And that's really difficult because we don't even see each other, let alone talk to each other, and we inhabit different cultures. (UK1)

Sometimes we feel at the hospital that we are quite poorly integrated. [...] [For example] the palliation is started on our part together with the patient, who goes to the hospital for some reason and has theoretically done everything, the therapy was stopped and everything is clear. And then comes some senior physician who says: 'we still have a chemo session for you which should be done'. No matter whether it is sensible or not. (G2)

To optimise IPC, most initiatives aim to disseminate a shared vision among HCPs in the wider community by showing the additional value of a proactive multidisciplinary palliative care approach through education and participation:

... the health care professional needs to be aware of the existing possibilities [of palliative care] and that is what you try to disseminate in a hospital. That, well, that individual contact with patients, that they [other healthcare professionals] will really experience the additional value of it. And to the outside you try to present this [palliative care vision] by providing education ... (NL5)

Patient flow

For most initiatives, ensuring that the right patients receive care at the right time from the right HCP depends on the knowledge of referring HCPs about palliative care and available palliative care services and whether HCPs are part of the extended network. Patient transfers are rarely based on standardised criteria, protocols or pathways. Participants report vulnerabilities during referrals and hospital discharges when HCPs in the wider community are involved.

Timely referrals to palliative care allow HCPs to develop relationships with patients and proactively identify and address problems and needs. However, according to participants, referrals often depend on HCPs who have insufficient knowledge of when to refer patients and are not always aware of available palliative care services. This particularly concerns patients with chronic obstructive pulmonary disease (COPD), heart failure and other non-malignant chronic diseases with prolonged disease trajectories and less clear prognosis compared to patients with cancer and for whom palliative care services appear less developed and less HCPs seem part of the extended network:

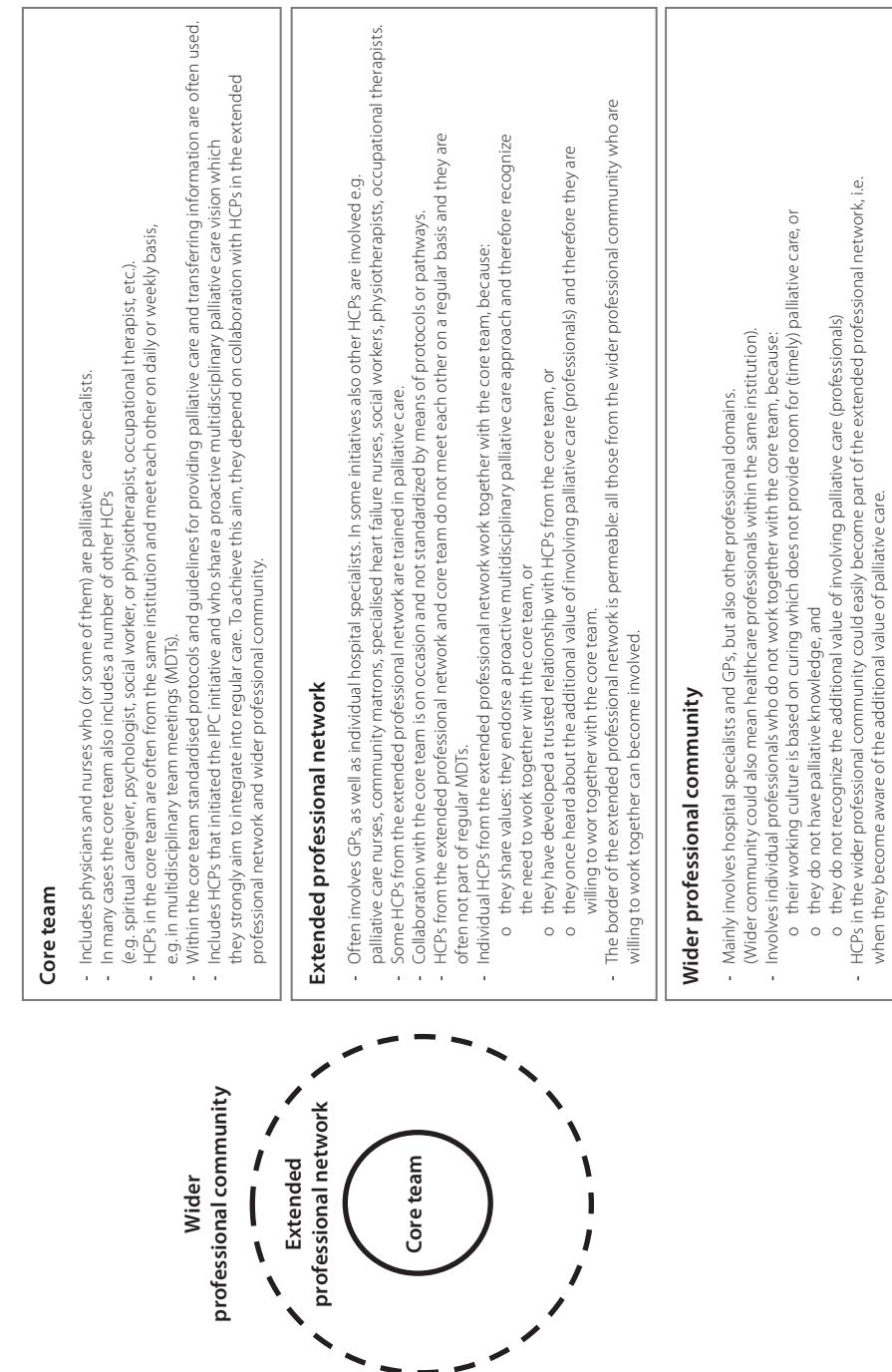


Figure 1 Illustration and explanation of the core team, extended professional network and wider professional community.

I think that currently it is still the oncologic patients whose disease courses are most tangible and clear. We have been increasingly come into contact with heart failure patients, with kidney patients, with COPD patients. But it is a lot less obvious how these [disease] trajectories will go. For these patients palliative care is far less being applied. Actually, I think that Oncology has been the starting point for us as palliative team and I feel that you still see that this is the greatest group of patients for whom palliative care is being involved. (B1)

[...] and I think the professional relationships are different with cancer, COPD and chronic heart failure. We're quite lucky: we know, (K), we know (T). (K) who works for COPD and (T) for heart failure [...] so I think the professional relationships are different and that doesn't have the same level of integration. (UK2)

Therefore, referrals still often occur too late:

We are often involved very late. And then they ask the team's support [...], but there is only little time left to be able to deal with all those [holistic] aspects. (B2–B3)

In order to encourage referrals, initiatives try to make referring HCPs part of their extended network, so that they become increasingly familiar with palliative care and the additional value of involving IPC initiatives:

[...] it has started with Oncology in the hospital and then the [other specialists] hear about it. You meet the entire hospital. So you're starting to involve others as well. That's how it happened with GPs as well. GPs who have good experiences with the palliative care network call more often. And they tell their colleagues: 'Have you already thought about [involving] [case managers palliative care]?' (NL3)

Hospital discharge also remains a challenge, especially for initiatives that are based in the community. *Currently we often get a phone call like: 'your patient is at home', or the GP calls: 'Oh it's a disaster', because someone has come home. We hurry to the home and find that nothing has been arranged. (B1)* For these initiatives often only particular units in the hospital are part of their extended network:

[Community Matron]: [...] the Discharge Co-ordinators which we have now started to build up a rapport and they know our patients and they'll ring to say, 'So-and-So is in hospital', and [...] as soon as they're medically fit, we'll go and see them. So they are improving but, as you say, it hasn't been rolled out totally. It's mostly on the medical respiratory wards that this is happening at the moment. (UK3)

Hospital-based initiatives report less difficulties with discharge, because HCPs from several hospital wards or in the community are part of their extended network and these initiatives have more possibilities to coordinate discharges themselves:

When the patient is still at the palliative station [palliative care unit] [...] we have already taken part in the preparation for the patient's discharge, the patient will have seen the negotiating partner and when the patient is at home, I pay a visit to check the home situation. At that point, community workers, [...] try to support the patient and the relatives. (G2)

Information logistics

Ensuring that the right information is available at the right time for HCPs requires smooth information transfer between HCPs involved in the patient's care. However, the quality of information transfer and the level of standardisation vary greatly among initiatives.

Participants report the highest quality of information transfer within the core team. These teams use a combination of communication channels and often standardise part of the information transfer specifically for core team members. For example, most initiatives have regular MDTs and some of them also use electronic systems to support information transfer. These systems are often only accessible to HCPs involved in the core team:

For the team, there are daily transmissions, weekly team meetings, which provide very good documentation in the computer system, I think, so that every point may be looked up regarding the current situation and the previous history. Especially important information is stored separately, as well, to make it more apparent. I think this is what is important. (G1)

Standardisation of when, how, which and with whom information is shared by means of protocols is not common. Nevertheless, because HCPs within extended networks and core teams know and trust each other, they have frequent contact, for example, by phone, face-to-face or personal notes, enabling information transfer:

[Communication] depends on [...] the personal relationships of the doctors. (HU1)

What really advances [information transfer] is when we know each other personally. [...] Not just on an institutional level. [...] We have an idea of the other's activities. It is easier to raise certain things, because we have a basic trust. And so, about what is inspiring and what causes obstacles. (G3)

However, according to HCPs within extended networks, barriers for information transfer also exist. For example, they are not automatically invited for regular core team MDTs or are not able to attend because their work schedules or locations do not permit them:

[Home help core team]: We don't see [extended network member] often [at the MDTs]. We know that they are involved with the family, but they are not present at the meeting.

[Nurse extended network]: And are we invited?

[Home help core team]: Well, I don't know. [...]

[Social worker core team]: It depends on the question, but actually it would be better if you also attended, wouldn't it? (BE2–3)

Limited standardisation of palliative care seems to be a predominant problem for the wider community, where HCPs are often not aware about the required information for providing IPC or lack any relationships with IPC professionals at all. Participants report that for this group information transfer is of limited quality, with the consequence that collecting the right information is often time consuming:

... a lot of the information we get is very poor, not very much at all. We spend a lot of our time digging for information, trying to ascertain exactly what's happened, what they've [referring healthcare professionals] had done, what they haven't had done, [...] what the plan is. It can take us a couple of hours. (UK3)

Furthermore, limited standardisation means IPC professionals continuously need to adapt communication to the personal preferences and locally used communication channels of individual HCPs. Empathy and maintaining goodwill seem important, but adapting to individual wishes can also be demanding:

I find it very difficult that some of them [GPs] have very heterogeneous expectations about when, at what time, they want to be informed. [...] There are no established basics in this area, and therefore, we always need a great deal of empathy and consideration because we can cause immense damage by failing to communicate. [...] The system is actually quite tiresome, because it can only really be met when there is a full understanding of the usual personal information requirements. (G3)

Availability of (human) resources and material

Whether initiatives are successful in ensuring that the right professional and the right medication and equipment are available at the right time largely depends on the country. However, for all initiatives out-of-hours accessibility appears challenging.

Generally, several initiatives face problems with the funding and availability of trained staff. Attempts to solve the problem of out-of-hours accessibility are done by the initiatives in two ways. First, they aim at avoiding crisis situations during out-of-hours by planning care proactively:

Weekend and night-time periods are critical, so we must always think and act proactively about the weekend or the night in terms of either symptoms or drug therapy, and we should really make ourselves available, because if they fail to reach us, they will call the ambulance or the on-call duty service. (HU2)

Second, they make sure that someone is on call to give advice if a crisis situation does occur. Several initiatives have telephone consultation lines (e.g. locally provided by hospices, regional consultation lines or private phone numbers of IPC professionals) and some have connections with general practitioner (GP) on-call services that are available out-of-hours. These services are highly regarded by HCPs in the extended network:

As a GP, it gave an infinite sense of security that I could keep the patient at home. I have received support from the hospice care in this regard and the patient could feel safe, too. If you encountered any problems even at weekends or at night, the hospice doctor was able to help immediately. (HU1)

However, HCPs in the wider community often appear not to be aware of the available services and this could result in unnecessary hospital admissions:

[...] if the patient receives hospice care, several issues can be planned in advance. However, at night and weekends, the situation is still very critical at times. It is a problem that a lot of patients are sent from nursing homes to emergency treatment centres at weekends, while it could be solved locally. (H3)

Most initiatives report difficulties obtaining medication during out-of-hours sometimes when medication has not been arranged in advance and regular pharmacies are not open. Therefore, many initiatives have a 'just-in-case' stock of medicines or materials at the patient's home or at the initiatives' location to ensure availability if the clinical situation of the patient changes after hours:

Medication in the weekend is sometimes difficult when we are on-call. Well, you are called to start a sedation or something [...] and then Dormicum is needed. Well, it was just recently that we needed to ask four pharmacies for medication. Well, that's such a shame [...] However, now we have a small stock [of medication] [...]. And recently I was very happy that I had this stock. (B2–B3)

Furthermore, several initiatives have included a pharmacy in their extended network to solve problems with the availability of medication, particularly during out-of-hours:

We have a good working relationship with a pharmacy, which is available to us at all times. [...] [Therefore] we are able to procure the patient's medicine the same evening. (G1)

Table 4 displays a summary of the barriers and enablers for each integrated care domain identified in this study. The model initiatives use to realise IPC is based on building core teams of palliative care specialists and extended networks rather than developing standardised information exchange and referral pathways. Shared values and mutual trust within core teams and extended professional networks enable palliative care provision at the right time provided by the right HCP. Educational activities enable enhancing a shared proactive multidisciplinary palliative care approach and extended networks. Informal contacts and electronic information systems allow for the right information to be available at the right time within core teams. Local solutions enable palliative care provision during out-of-hours. However, due to its informal nature and limited scope, integration of palliative care remains fragile and is jeopardised beyond extended networks. Furthermore, lack of (funding for) trained staff, medication and material hamper continuity of palliative care and oblige initiatives to use provisional solutions.

Table 4 Summary of barriers and enablers for each domain of integrated palliative care identified in this study.

	Barrier	Enabler
Content of care	Lack of palliative care knowledge/ awareness among healthcare professionals in the wider professional community and therefore lack of a shared proactive multidisciplinary approach	Shared proactive multidisciplinary palliative care approach Extended professional networks Education
Patient flow	Lack of awareness of available palliative care services Lack of referral criteria, protocols and pathways	Extended professional networks
Information logistics	Lack of widely shared electronic information systems or information transfer protocols Multidisciplinary team meetings not always accessible beyond core teams	Use of (electronic) information systems (although mainly within core teams) Multidisciplinary team meetings, personal notes, phone calls Extended professional networks
Availability of (human) resources and material	Lack of (funding for) trained staff Lack of out-of-hour availability of staff, medication and material	Local solutions, such as on-call (consultation) services within small teams Just-in-case stocks for medicines and material Extended professional networks including pharmacies

Discussion

This study examined how IPC takes shape across four domains: content of care, patient flow, information logistics and availability of (human) resources and material. We identified core teams, extended professional networks and the wider professional community to provide several limitations and enablers for better integration of palliative care. Enablers allow the initiatives to provide IPC on a small scale on informal basis within core teams and extended networks. However, initiatives report difficulties realising IPC in the wider community because these HCPs often do not share a proactive multidisciplinary palliative care approach, they do not know palliative care professionals personally and they do not have frequent contact.

Several studies^{16, 28} confirm that inter-professional teamwork based on trust and shared knowledge, norms and values is an essential enabler for successful integrated care. Other studies^{19, 20} underline that educational activities to make HCPs aware of and skilled in palliative care are an important element of IPC models. Moreover, expansion of basic palliative care training is seen as an important enabler for the integration of palliative care^{21, 29}. However, the difficulties to integrate palliative care into the wider community due to barriers, such as a lack of palliative care knowledge and shared values, have been underlined in the literature as well^{30, 31}. Since many HCPs have insufficient knowledge about what palliative care is, regard it as part of what they already do or consider it merely as terminal care and are focused on curing a disease^{21, 30, 31}, they do not recognise the additional value of collaborating with palliative care professionals.

Multidisciplinary teamwork and consultation are important components of horizontal integration^{28, 32}. Comprehensive integration, however, also requires vertical integration, considered as adjacent levels in a chain of care³². The initiatives in our study provide promising examples of vertical integration by starting from primary, secondary or tertiary care level and building relationships with HCPs working at other levels. However, many initiatives met difficulties particularly during transitions (referrals and discharge) suggesting that there is room for improvement, for example, using standardised care pathways.

The initiatives did not often make use of standardised care pathways, guidelines or electronic information systems beyond core teams. However, according to Fabbricotti¹⁶, aligning tasks and procedures is one of the prerequisites for achieving enhanced integration. Although rigorous research on standardised information exchange in palliative care is lacking³³, literature shows that palliative care is only integrated in guidelines for cancer and chronic care to a limited extent^{34, 35}, let alone its implementation into practice. Moreover, pathways and tools that guide HCPs to refer patients to palliative care in a timely way are being developed, but are not all validated yet¹⁷⁻¹⁹.

Although enhanced standardisation, such as the implementation of pathways and guidelines, is seen as an enabler for palliative care integration²⁹, this is probably not enough to fully realise integration. HCPs in the wider community first need to value the integration of palliative care in their clinical practice. Therefore, they need to explore and experience the surplus value of integrating palliative care. Examples are the recent integration of palliative care into oncology guidelines³⁶ and the series about integration of palliative care into patients with COPD recently published in the Lancet³⁷. However, despite these promising examples, changing the attitudes among longstanding internal medical disciplines and GPs still remains a difficult task that will take time and effort. Apart from building relationships and educational activities which were enablers in this study, enhanced evidence base is also seen as an enabler for palliative care integration²⁹. However, the optimal way to organise IPC in relation to patient satisfaction and clinical outcomes requires further research. Future research could, for example, focus on piloting implementation of a promising IPC model and conducting before and after implementation interviews with both HCPs and service users. Despite research and expert consultation, some prerequisites for achieving further integration are beyond the direct influence of palliative care professionals, including funding for trained palliative care staff, palliative care reimbursement, enhanced regulation and legislation^{21, 29}. Therefore, support from external authorities, such as policy makers, insurance companies, research programmes and professional bodies, will probably be needed to fully achieve IPC.

Strengths and limitations

A large international group interview study with selected IPC initiatives in five European countries is a great and unique platform^{18, 30, 38}. It enabled collecting valuable in-depth data about how integrated care takes shape in practice within current IPC initiatives in Europe from the perspectives of HCPs. Due to the complex international context, it was difficult to fully achieve an iterative process³⁹ of simultaneous data collection and analysis. Therefore, the data are possibly not as rich as intended. Although it would have been useful to describe examples of good practice of integration, this was not the focus of this article. However, detailed descriptions of some promising models in the InSup-C project have been described elsewhere⁴⁰.

Conclusion

This study suggests that building core teams of palliative care specialists and professional networks based on personal relationships, shared norms and values and mutual trust is the dominant strategy for fostering IPC. However, convincing the wider community in order to achieve better integration into regular healthcare is a difficult task that will take time and effort. Moreover, enhancing standardisation of palliative care into education,

referral pathways, protocols and guidelines as well as standardised information exchange may be needed as well. External authority will probably be needed to support IPC practices across settings. These insights should be prioritised by professional bodies, insurers and policy makers in order to promote IPC for patients with various disease backgrounds.

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8

General discussion

The aim of this thesis was to examine how integrated care is currently implemented in the clinical practice of preselected palliative care initiatives in several European countries. The studies that form this thesis were part of the InSup-C project funded by the European Union Seventh Framework (EU FP7) Program. In this chapter, I present the main findings and discuss these in light of the relevant, recent literature. I conclude with recommendations for clinical practice, research, education and policy.

Main findings

Design of an international study on integrated palliative care

In Chapter 2, I described the protocol for the prospective multiple embedded case study. We assumed that selecting a number of palliative care initiatives in different European countries and examining these in-depth would provide valuable understanding of how integrated care is currently implemented in the clinical practice of front running palliative care initiatives. We considered a multiple embedded case study design using mixed methods appropriate to achieve this aim. However, there was no theoretical framework or prevailing standard for integrated palliative care we could use for the selection of palliative care initiatives. Therefore, in order to investigate palliative care initiatives where integrated care was already visible, the InSup-C project team agreed on a number of criteria¹ (Table 1) and developed a working definition (discussed below) as a basis for the selection of specific initiatives. Other international research groups investigating integrated care for older people have also used case study designs and comparable selection criteria^{2, 3}.

The initiatives were not selected ‘at random’, but were preselected with the help of the InSup-C research team and by consulting (inter)nationally respected experts in palliative and integrated care. This selection method was considered appropriate as we aimed to generate in-depth insights in current integrated care implementation in palliative care initiatives, instead of providing a comprehensive overview of integrated palliative care services within countries or throughout Europe. The studies conducted within InSup-C^{4, 5} and specifically within the initiatives⁶⁻⁹ ultimately provided valuable insights into how integrated care is currently implemented in the clinical practice of preselected palliative care initiatives (hereafter integrated palliative care initiatives) in five European countries. A particular strength of this thesis is that it includes the perspectives of patients and family caregivers, which is unique for such a large scale project^{2, 10, 11}. As integrated care ultimately aims to achieve a coordinated care process for each individual patient, it was crucial to obtain insights into the views of patients in palliative care trajectories and their family caregivers with regard to how their care is provided by the healthcare professionals in their care network.

Table 1 Selection criteria for integrated palliative care initiatives.

1	The initiative is an established local palliative care collaboration
2	The collaboration must contain at least two different organisations
3	A hospital can be part of that collaboration
4	Collaborating healthcare professionals must provide direct patient care (not only an advisory function)
5	The collaboration has a multidisciplinary background (professionals of different professions must be involved, e.g. physician (specialist, GP), nurse (specialist), social worker, Allied Health Professional, spiritual worker, complementary therapist, others)
6	The collaboration aims to provide palliative care for one or more target diagnostic groups in the study (COPD/CHF/Advanced cancer)

COPD: ChronicObstructivePulmonaryDisease; CHF: ChronicHeartFailure

Definition of integrated palliative care

Since integrated palliative care was an unexplored field at the start of this study, we were unaware of any existing definition of this specific concept, although there are more general definitions for integrated care. In Chapter 2, I describe a working definition of integrated palliative care formulated at the beginning of the InSup-C project. This definition was based on commonly used definitions of integrated care for chronically ill patients¹²⁻¹⁵ and refined to the context of palliative care¹⁶. The working definition is:

“Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid”¹

The definition was discussed extensively at international InSup-C project meetings until general consensus was reached. The definition seems applicable, as it includes aspects of integrated palliative care at a micro, meso and macro level, and focuses on all stakeholders involved in palliative care provision. After the definition was agreed within the international InSup-C project team, as part of the InSup-C project, the definition was discussed with an international multidisciplinary focus group⁵ and at a European Association of Palliative Care (EAPC) conference meeting (‘meet the expert’ session, EAPC Copenhagen, May 2015).

During these meetings, the concept of continuity of care in the definition was considered essential for integrated palliative care, to contrast this with current regular palliative care provided by individual healthcare providers⁵. However, suggestions for refinement were also received. For example, the definition should focus on “all patients in need of palliative

care” instead of those “receiving palliative care”⁵. This makes the definition more inclusive for patients with non-malignant illnesses who are less likely to receive integrated palliative care, as shown in our study⁹. Moreover, “all patients in need of palliative care” also means that appropriate and timely identification of patients is needed. Furthermore, the definition should put more emphasis on the early application of palliative care in the treatment trajectory and not only on “the dying process”⁵ (discussion during ‘meet the expert’ session, EAPC Copenhagen, May 2015). Taking these suggestions into account, an adjusted integrated palliative care definition reads as follows: *“Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients with palliative care needs. It is applicable early in the illness trajectory and aims to achieve optimal quality of life and/or optimal quality of dying and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid.”* This adjusted definition needs to be further validated.

The main findings of the studies conducted in Chapter 3-7 provide insights in the perspectives of patients, family caregivers and healthcare professionals on integrated palliative care as well as on health system aspects. These findings are, therefore, highly appropriate for categorisation at the three levels of integrated care described in the Introduction: the micro, meso and macro level. Table 2 presents an overview of the studies conducted in chapter 3-7.

Table 2 Overview of studies conducted in this thesis

Chapter	Topic	Countries	Number of initiatives	Participants	Design	Integrated care level
3	Care networks	BE, DE, HU, NL, GB	22*	157 patients	Cross-sectional explorative study	Micro
4	Continuity of care	BE, DE, HU, NL, GB	22	152 patients 92 FCs	Qualitative interview study	Micro
5	Participation	NL	5	31 patients 22 FCs	Secondary qualitative analysis	Micro
6	Current IPC implementation	BE, DE, HU, NL, GB, ES, IE	n/a	34 leaders in PC or integrated care	Qualitative interview study	Meso, Macro
7	Current IPC implementation in daily practice	BE, DE, HU, NL, GB	19	142 HCPs	Qualitative group interview study	Meso, Macro

IPC: integrated palliative care; FC: family caregiver; PC: palliative care; HCP: healthcare professionals.
*The number of initiatives in Chapter 3 differs from the number of initiatives described in this general discussion. InSup-C started with 23 integrated palliative care initiatives, but one of the initiatives in Germany dropped-out, due to the lack of inclusion of patients.

At the micro level

As described in the Introduction, integrated care at the micro level focuses on achieving a coordinated care process for the individual patient¹⁷. Our studies on the experiences of patients and family caregivers with integrated palliative care provide insights into micro level integrated palliative care.

The experiences of patients and family caregivers with integrated palliative care

Three studies were conducted in order to gain insights into the experiences with integrated palliative care of patients with advanced Cancer, Chronic Obstructive Pulmonary Disease (COPD) and Chronic Heart Failure (CHF) and their family caregivers receiving care from integrated palliative care initiatives in Belgium, Germany, Hungary, the Netherlands and the United Kingdom. Chapter 3 describes a cross-sectional explorative study investigating the composition and perceived integration of care networks of 157 patients as well as whether perceived integration between healthcare professionals was associated with overall satisfaction. Chapter 4 describes a qualitative interview study with 152 patients and 91 family caregivers, examining how they perceived continuity of care. Chapter 5 describes the results of a secondary qualitative analysis of how participation of patients and family caregivers in palliative care trajectories was shaped, based on the perspectives of 31 Dutch patients and their 22 family caregivers.

Ensuring continuity of care in order to promote integrated palliative care

Notwithstanding differences in the organisation of care networks between the integrated palliative care initiatives examined, Chapter 3 shows that patients were generally satisfied with care provision and in particular with their relationships with palliative care physicians. Moreover, in this study sample, better perceived integration (collaboration and coherence) between healthcare professionals in the patient's network was associated with higher satisfaction of patients. Furthermore, in Chapter 4, continuity of care – defined as :“the extent to which a series of health care services is experienced as connected and coherent and is consistent with a patient's health needs and personal circumstances”¹⁸ (Box 1) – was identified as an essential theme for the experiences of patients and family caregivers with palliative care provision. Other studies also found that continuity of care is crucial in palliative care provision according to patients and family caregivers¹⁹⁻²¹. Our findings suggest that perceived continuity of care is more important to patients and family caregivers than exactly the way their care is organised and which healthcare professionals provide it. Thus, in order to enhance integrated palliative care, initiatives should ensure continuity of care at the micro level (the patient and family caregiver level). Although regional contexts may require regional solutions, in Chapters 3 and 4, we identified common elements for patients and family caregivers from different cultural backgrounds

considered important for securing continuity of care. These elements include: appropriate coordination of the care network, having a small number of trusted healthcare professionals and interdisciplinary teamwork.

Coordination of the care network

It was found^{22, 23} that often large numbers of healthcare professionals are involved in care networks of patients with advanced CHF or cancer, making these care networks complex. Our findings show that for patients in a palliative care trajectory, it can be complex to understand the roles of the individual healthcare professionals participating in the care network. Although patients in Chapter 3 were recruited from integrated palliative care initiatives, it was uncommon for many of them to explicitly report on (specialist) palliative care professionals within their care networks, especially for patients with COPD and CHF. Additionally, many patients perceived more than one healthcare professional or caregiver to be the main people responsible (including family caregiver, patient, nurse, general practitioner, palliative care physician and/or hospital specialist) for organising their care. Additionally, most patients in Chapter 3 identified the general practitioner as being present in their care network. However, according to patients and family caregivers, in Chapter 4 the general practitioner did not by definition have a key role in the patient's care network. Although patients were no longer in a curative trajectory, a number of patients and family caregivers perceived that general practitioners tended to take the backseat when medical and/or palliative care specialists were involved. Some of them reported that they missed the involvement of the general practitioner in their care provision. This finding is surprising, given that the general practitioner is often considered to play a key role in palliative care^{24, 25}. Overall, these results show that for patients in our study, the roles of healthcare professionals in the care network were not always clear, that palliative care specialists were not always present or visible in the perspective of patients, that many patients could not clearly identify a key healthcare professional, and that some general practitioners were involved in palliative care networks to a limited extent. Whether patients prefer having one single key person in their care network and what tasks and responsibilities this person should have, requires further research. However, our findings suggest that in order to enhance continuity of care for patients, in a palliative care trajectory healthcare professionals should navigate patients and family caregivers through the patient's care network and make clear who their first contact person is in case of need. Hereby, the important role of the family caregiver in the patient's care network (Chapter 3, 7) also needs to be taken into account. Additionally how to improve to role of the general practitioner in the patient's palliative care network needs more research.

A small number of healthcare professionals and interdisciplinary teamwork

Pivotal for promoting continuity of care from the perspective of patients and family caregivers in our study was the ready availability of a small number of trusted and

approachable healthcare professionals. Receiving care from healthcare professionals who know you and are aware of your clinical and personal context provides a feeling of trust and security^{6, 19}. However, we observed that in the context of palliative care with complex patients, often a great number of healthcare professionals from different disciplines were involved. This reduced the possibility for patients to see the same healthcare professional each time. Moreover, in Chapter 4, patients and family caregivers often reported a lack of information transfer and consultation between healthcare professionals who were not involved in the integrated palliative care initiatives, which limited their perceived continuity of care. Other studies show that a lack of coordination²⁶ and inadequate information transfer²¹ often jeopardise patients' and family caregivers' perceived continuity of care. These findings emphasise that close collaboration, i.e. interdisciplinary teamwork, between all healthcare professionals involved in the patient's care trajectory, is essential for securing continuity of care. In Chapter 7, healthcare professionals involved in the integrated palliative care initiatives pursued interdisciplinary teamwork by sharing a common proactive palliative care vision, making joint treatment plans, and frequently exchanging information. Similarly, Klarare et al.¹⁹ found that specialised palliative care teams provided interdisciplinary teamwork, using a united approach to care provision. Although different healthcare professionals were involved, patients and family caregivers experienced continuity of care¹⁹. Our results suggest that, based on the perspectives of patients and family caregivers, enhancing interdisciplinary teamwork between all healthcare professionals involved in the patient's care network is needed to improve perceived continuity of care. This requires healthcare professionals to work towards a shared goal setting, have a high level of knowledge about each other's working methods and competences, as well as having a clear delineation of roles, tasks and responsibilities^{27, 28}. This also requires healthcare professionals to have specific competencies for working in a care network. Interestingly, as an example, the Dutch federation of medical specialists (FMS) produced a vision document about the medical specialist of the future²⁹. It states that the medical specialist of the future is not merely a super-specialised physician, but is someone who is able to operate in a care network and provides (shared) care based on the specific needs of the individual patient. This requires training in specific competencies such as being able to work together with other disciplines, having communication/negotiation skills, showing empathy, and being creative³⁰. However, these competencies are not only needed for medical specialists, but for all healthcare professionals in the patients' care network, as well as for the patient and family caregiver. Moreover, our definition suggests that in order to achieve integrated palliative care, interdisciplinary teamwork between healthcare professionals, patients and family caregivers alone is not enough. The involvement of professionals who are responsible for achieving the administrative and organisational aspects of integrated palliative care is also needed. The specific way in which these (healthcare) professionals should collaborate, the optimal role division, and the identification of key figures in a new model of care provision requires further research.

Box 1 Important definitions used in this thesis

Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid¹.

Continuity of care from the perspectives of patients is defined as the extent to which a series of healthcare services is experienced as connected and coherent and is consistent with a patient's health needs and personal circumstances¹⁸.

Multidisciplinary teamwork means that people with different disciplines or professions have input in the treatment of a patient each from their own professionalism and expertise. This type of teamwork is not necessarily accompanied with active collaboration or joint meetings, instead the term 'multidisciplinary' points to the composition of a team²⁷.

Interdisciplinary teamwork is characterised by healthcare professionals who share a common goal and use interprofessional discussion to work towards a shared treatment plan. This requires insights in the other disciplines and the willingness to question one's own work. This form of teamwork involves the contribution of the patient and /or family caregiver in setting up the treatment plan²⁷.

Patient participation means that the content, planning and organisation of the patient's care process is based on mutual agreement between the patient and his/her healthcare professional(s)^{31, 32}. Patient participation also includes the active involvement of patients and their family caregiver(s) in each step of the care process, not only in making decisions about medical treatment³².

Participation of patients and family caregivers

Integrated care involves patients as partners of healthcare professionals in making sure that care is coordinated around their needs³³, suggesting their active participation. Patient participation means that the content, planning and organisation of a patient's care process is based on mutual agreement between the patient and the healthcare professionals^{31, 32}. Patient participation is more than 'shared decision making', and includes the active involvement of a patient and his/her family caregiver in each step of the care process, not only in making decisions about medical treatment³². Patient participation is increasingly recognised as an essential element of healthcare provision. For example, having specific guidelines for patient participation is one of the requirements for the accreditation of safety management systems in Dutch hospitals³⁴. However, compared to curative trajectories, in palliative care trajectories, participation may be even more important, as patient preferences at the end of life are often individually determined³⁵.

In Chapter 5, we identified seven forms of participation of patients and family caregivers in palliative care trajectories in the Netherlands. Our study underlined³⁶ that there is no uniform way or optimal model for participation of patients and family caregivers. Participation is dynamic and depends on the individual preferences and characteristics of patients and family, and it depends on factors such as illness narratives and stage of the illness^{37,38}. Despite increasing recognition of the importance of participation in healthcare policies, patients' or family caregivers' expectations about participation sometimes conflicted with the reality of clinical practice (Chapter 5). Healthcare professionals did not always offer the opportunity for patients and family caregivers to participate actively. However, patients and family caregivers also differed in their ability or preferences to influence participation. Moreover, at the end of life, patient participation becomes increasingly challenging because of the patient's deteriorating condition.

Many studies on participation focus on the patient physician dyad³⁹. However, it is just as essential to enable participation of family caregivers. Family caregivers often have a significant role concerning supporting the patient and in ensuring quality and coordination of the patient's palliative care trajectory^{7,40}. In a few instances in our study, however, some family caregivers had a dominant role which potentially prevented the patient from discussing his/her own preferences and possibilities. This role may be problematic if it is incongruent with the patient's preferred level of participation. Our findings show that it is important to ensure that participation is congruent with the wishes of both patients and their family caregivers, and that it should be offered within the specific clinical circumstances. The condition of the patient on the one hand and clinical circumstances on the other can limit the level of patient participation and/or the number of treatment possibilities left^{36,38,41}.

These factors emphasise that defining the appropriate level of participation may be complex and requires coordination. Therefore, defining the appropriate level of participation should result from a dialogue and sometimes even negotiation process throughout the palliative care trajectory. In this process, healthcare professionals, patients and family caregivers have joint responsibilities. Patients and family caregivers need to make their preferences for participation explicit and adopt a collaborative attitude if they want to participate. Empowerment strategies^{32,42,43} like communication skills training or self-management interventions can be useful for patients and family caregivers to increase their level of participation. However, at the same time, healthcare professionals also play a crucial role in facilitating and making a dialogue explicit early in their patient's illness trajectory. This also requires healthcare professionals to adopt an open, proactive and person-centred approach towards patients and their family caregivers (Chapter 5,^{31,44}).

From a patient and family perspective, integrated palliative care at the micro level requires continuity of care by a well-coordinated care network and interdisciplinary teamwork. The healthcare professionals involved in the palliative care trajectory should identify the appropriate level of participation of patients and family caregivers by adopting a person-centred attitude and by facilitating a dialogue between the patient, family caregiver and healthcare professional throughout the care trajectory. Patients and family caregivers should make their preferences for participation and their choices and needs concerning treatment explicit.

At the meso level

Integrated care at the meso level focuses on reducing organisational compartmentalisation and promoting collaboration and interdisciplinarity between the staff that provide the service. The perspectives of healthcare professionals on the current implementation of integrated palliative care provide insights in the meso level of integrated palliative care.

Perspectives of healthcare professionals on integrated palliative care

We conducted two studies to obtain insights in the current implementation of integrated palliative care in different European countries. In the first study, described in Chapter 6, we examined the perspectives of 34 experts in 7 European countries on how integrated palliative care is currently implemented, and described the facilitators of and barriers for integrated palliative care. In the second study, Chapter 7, we examined the perspectives of 142 healthcare professionals on integrated palliative care involved in 19 integrated palliative care initiatives in 5 European countries. Both studies provided in-depth insights into how integrated palliative care is currently implemented in daily practice. In Chapters 6 and 7, we demonstrated that a key mechanism for integrated palliative care includes interdisciplinary teamwork. Specifically, according to healthcare professionals in Chapter 7, the dominant strategy for fostering integrated palliative care is building core teams of palliative care specialists and extended professional networks based on personal relationships, shared norms, values, and mutual trust. What the specific role of the coordinator (general practitioner or another healthcare professional) of the professional network is, or should be, was not the focus of our study and needs to be further investigated. Information transfer and referrals of patients mostly occurred in interdisciplinary meetings and through existing professional relationships. However, standardised information systems such as electronic patient records were often restricted to individual organisational settings or stand alone palliative care teams, but were rarely accessible across a network or region. Building relationships and educational activities promoted the development of a shared proactive interdisciplinary palliative care approach, as reported in Chapter 7.

Integrated palliative care is based on professional networking rather than systematic implementation

Aligned to our findings, other studies emphasise that developing shared norms and values and building professional networks are essential and powerful strategies for achieving integrated care^{33, 45, 46}. Moreover, we, in Chapter 6 and others⁴⁷ indicate that integrated palliative care is also facilitated by a general increase in awareness among healthcare professionals and the general population of the need for person-centred palliative care. In order to enhance integrated palliative care, these elements should be the foundations of palliative care initiatives. However, our study suggests that this is not enough, because at the same time, the basis of most of the integrated palliative care initiatives was fragile due to their informal nature and their limited scope. Healthcare professionals in Chapter 7 reported that although transferring information via informal ways was considered effective, this was often time consuming. This could be due to the lack of systematic information exchange and the lack of widely accessible information systems observed in most integrated palliative care initiatives. Timely referral of patients was often problematic, which could be partly due to a lack of timely identification and an absence of widely used referral pathways in most integrated palliative care initiatives. The absence of systematic information exchange and referral pathways can hamper structural professional collaboration. For patients with complex needs, as professional networks grow due to the networking activities of palliative care professionals, maintaining informal ways of information transfer and patient referrals may become exhausting and time consuming. Our results indicate that in order to ensure that all patients in need of palliative care receive it at the right moment, palliative care should be more proactively and systematically integrated into disease-oriented care trajectories. Systematic methods for the proactive identification of patients with palliative care needs, referral pathways²⁴, and/or guidelines, may promote timely and systematic implementation of integrated palliative care by healthcare professionals. Guidelines or pathways for integrated palliative care are still being developed⁴⁸⁻⁵⁰, although a few good examples of guidelines can be found^{51, 52}. With regard to information transfer, promoting structural collaboration among healthcare professionals providing integrated palliative care will require information systems that are accessible to all healthcare professionals involved in a care network. These information systems will need to comply with the European privacy legislation, potentially making them complex, expensive to develop and limiting integrated palliative care. This also requires active patient participation, since the patient needs to agree with sharing his data between healthcare professionals within integrated palliative care programs.

Professional awareness, knowledge and expertise of palliative care

Despite the acknowledged general increase in awareness of palliative care, our study highlighted that integrated palliative care remains limited to local initiatives of palliative care teams and their extended professional networks. Penetration into a wider professional

community, let alone at a national level, remained difficult. Healthcare professionals in Chapter 7 attributed this to the lack of a shared proactive palliative care vision among healthcare professionals with other backgrounds than palliative care, and to a general lack of knowledge on the availability of palliative care services. Similarly, other studies show that among healthcare professionals with other backgrounds than palliative care, there is a lack of clarity about the meaning and additional value of integrating palliative care and a lack of knowledge about when and how to integrate care⁵³⁻⁵⁵. It was found^{53, 54} that many healthcare professionals still focus on curing a disease, and regard palliative care as part of what they already do, or consider it 'merely' as terminal care. In order to increase the awareness and knowledge about palliative care among healthcare professionals, a number of measures at both the meso and macro level need to be taken. Palliative care should be structurally incorporated at all levels into educational programmes for medical students and trainees. An example is the PASEMECO⁵⁶ (palliative care in medical education) project in the Netherlands, which focuses on achieving integrated palliative care in the undergraduate curricula of all Dutch medical students. The development of an evidence base for the effectiveness of palliative care also needs to be promoted, as this may enhance professional awareness of integrated palliative care⁴⁷. Additionally, a normative quality framework stating the meaning and surplus value of palliative care as well as how and when to provide this may help to increase awareness about palliative care among healthcare professionals. Initiatives like these will require external support from the ministries of health, insurance companies and professional bodies. A useful example is the support and funding from the Dutch government in order to ensure that by 2020, every citizen will receive palliative care at the right place, at the right moment, from the right healthcare professional, at the right time⁵⁷. Part of this is the development and implementation of a quality framework of palliative care, including requirements for palliative care models in collaboration with several professional bodies. However, the further implementation of integrated palliative care also requires a cultural shift, and this will take time. The recent integration of palliative care into oncology guidelines⁵⁸ and implementation of palliative care guidelines into disease-specific trajectories like chronic obstructive pulmonary disease (COPD) recently published in the *Lancet*⁵⁹ are promising examples, showing that a cultural shift is gradually taking place.

In order to enhance integrated palliative care at the meso level, developing a shared proactive palliative care approach is essential. Awareness of palliative care and the knowledge and expertise of healthcare professionals with other backgrounds than palliative care should be increased, and strategies to systematically implement integrated palliative care should be promoted.

At the macro level

Integrated care at the macro level focuses on coordinating and aligning national and regional finance schemes, policies and regulations that promote integration of fragmented (health)care services^{17, 45}. Healthcare professionals in our studies identified a number of macro level barriers for integrated palliative care.

A lack of funding and regulation

Healthcare professionals involved in the integrated palliative care initiatives reported that a lack of (funding for) trained staff, medication, and equipment, hampered continuity of palliative care. These barriers jeopardised out-of-hours access to palliative care and obliged initiatives to use provisional solutions, for example using just-in-case stocks of medicines. In Chapter 4, we report that in the view of patients and family caregivers, continuity of care was promoted when healthcare professionals were readily available. This was also supported in other studies^{19, 60}, implicating a 24/7 availability of palliative care teams. However, in Chapter 7, we show that in many integrated palliative care initiatives, providing 24/7 palliative care can be problematic due to the lack of trained staff and financial resources. Notwithstanding, limited financial resources can also incite integrated palliative care initiatives to invent creative solutions. For example, one rural initiative examined in the InSup-C project decided not to invest in a central building due to scarce finances, but in healthcare professionals who moved around a geographic area to visit patients at home⁶¹. However, it was also suggested that the lack of trained staff means that palliative care provision often relies on the efforts of individual healthcare professionals, but is not secured in the long term⁶¹. Whilst the problems found in our study with a lack of trained staff and the difficulties that integrated palliative care initiatives met ensuring continuity of out-of-hours care became evident at the meso level, structural solutions are most likely to be found at the macro level. These particularly relate to funding and regulation.

Studies^{47, 62} showed that in some countries, macro level solutions have promoted integrated palliative care in national health systems. These, for example, include the implementation of laws dedicated to palliative care⁶² and the acknowledgement of palliative care as a medical specialism⁴⁷. However, at the same time, it was noted^{47, 55} that the macro level aspects of education and finance still form major barriers to further integrated palliative care. Palliative care reimbursement is often unable to cover trained palliative care staff^{63, 64}, and funding for education and research^{47, 63} is still limited. Furthermore, a number of European countries lack regulatory frameworks for integrated palliative care, and if they exist at all, they are mostly directed at cancer^{47, 65}. It was found⁶⁶ that in several European countries, financial arrangements for palliative care are diagnosis-specific, instead of being based on the expected needs of palliative populations. These arrangements are often in favour of cancer care trajectories, but are limited to terminal

illness, and do not include the early application of palliative care in these trajectories, nor the longer lasting palliative care trajectories of patients with non-malignant illnesses^{61, 66}. Moreover, studies indicate that arrangements often do not finance integrated palliative care programmes as a whole, but rather promote isolated healthcare provision like consultation facilities^{24, 66}. As the palliative care needs of patients throughout Europe are expected to increase dramatically by 2040^{67, 68}, enhancing integrated palliative care at the macro level should be a high priority. This is also indicated by the World Health Organization resolution on palliative care that urges nations to integrate palliative care into their health systems⁶⁹. In order to promote integrated palliative care for all patients who need it, funding should be based on the population in need of palliative care. Which specific funding mechanisms promote an integrated provision of palliative care for patients with (non-) malignant disease requires further research. External support by policy makers, ministries of health, insurance companies, research programmes, and professional bodies will therefore be required.

In order to improve integrated palliative care at the macro level, regulation and funding need to be redesigned to improve the structural support for integrated palliative care programmes as a whole for palliative patients with malignant and with non-malignant diseases, and to ensure sufficient trained staff, medication, institutional structures and equipment.

Methodological considerations of the presented research

The large international qualitative study with preselected palliative care initiatives in five European countries, is a significant and unique platform for collecting valuable in-depth data about how integrated care is implemented in current palliative care initiatives^{50, 53, 70}. This was not only examined from the perspectives of healthcare professionals as in previous EU FP7 projects on the organisation of palliative care in Europe^{10, 70}, but also from the perspectives of patients and family caregivers. The use of multiple data sources in this study (triangulation)⁷¹ provided deeper insights into how integrated palliative care is implemented. Moreover, the international nature of the study enabled the identification of certain results (e.g. that patients were generally satisfied with care provision even though care networks were organised differently) and commonalities across countries that would not have been found if only a single country or setting had been investigated. This thesis largely focused on the perspective of patients and family caregivers, and to a lesser extent on that of healthcare professionals. Since patients and family caregivers may not always have an adequate understanding of how their care is organised, this may have caused bias, e.g. in the results about the composition of patient's care networks or the role of the general practitioner. Notwithstanding, the perspective of patients and family

caregivers provides important information about potential gaps in service provision, making them highly valuable, if not indispensable, for improving integrated palliative care. The studies conducted in this thesis demonstrate that integrated palliative care predominantly takes place at the micro and meso level. Therefore, these levels also predominate in this general discussion. On the one hand, this may be inherent to the methodology used in this thesis: the level at which integrated palliative care was analysed mainly focused on the patient, family caregiver and healthcare professional perspective. The exploration of the organisational and structural aspects were restricted to the reports of patients and professionals, but within the involved institutions these aspects were only investigated to a limited extent as we only collected basic information about the organisational set up of the initiatives. On the other hand, the predominance of micro and to a lesser extent meso level strategies to achieve integrated care is consistent with other studies which found that integrated care at the macro level is less often represented^{46, 72, 73}. Successful integrated care requires efforts at all levels^{45, 46}. Macro level aspects like the absence of structural and financial resources often form a major barrier to integrated palliative care^{47, 63}. Therefore, more efforts should be made to investigate how to achieve integrated palliative care at the micro, meso as well as the macro level.

Although all integrated palliative care initiatives we examined aimed to provide care for patients with both cancer and chronic disease, the majority of patients receiving care in these initiatives had cancer⁹. This reflects the population of patients currently receiving palliative care^{11, 74}, since in many European countries specific programmes to identify patients with non-malignant disease are not yet available. Therefore, even though we aimed at including initiatives directed at patients with advanced cancer, COPD and CHF, the latter two, especially those with CHF, were often difficult to identify, or patients dropped out during the study. The predominance of patients with advanced cancer in our study may have caused bias, meaning that the way integrated palliative care is implemented from the perspectives of patients and family caregivers with COPD and CHF is underrepresented. These problems stress the importance of prioritising research on services provision and guideline development for patients with non-malignant illness.

Preselecting initiatives had the advantage of generating insights in how integrated palliative care is experienced in daily practice. However, the results were not meant to be representative for whole countries and patient groups. A (preferably mixed-methods⁷⁵) study with a representative sample of each country and patient group would be needed to investigate country performance. However, this was not the aim of our study, and this may require a policy approach instead of (or along with) research.

An international study has the potential risk of methodological inconsistencies. In order to enable comparison of international data and ensure methodological rigour, uniform

research methods across all countries were used. The German and Hungarian group interview transcripts with healthcare professionals were translated into English for the analysis (Chapter 7). Training sessions were organised for researchers that focused on preparing and conducting interviews, performing reliable and valid qualitative research codebooks, and processing data (Chapter 4). Additionally, pilot (group) interviews were conducted, a uniform international codebook was developed, and the study progress and results were frequently discussed and compared with the researchers in each country in face-to-face and Skype meetings and by e-mail.

The predominance of a researcher interpreting data from other countries could potentially involve researcher bias, meaning that the preconceptions of a researcher from one country could influence data selection and analysis⁷⁶. This bias was limited as much as possible by analysing the preliminary results with two or more researchers, and by developing a preliminary (internationally agreed) codebook (Chapters 4 and 7) in the early stages of the study. Furthermore, the preliminary and final results were peer reviewed within the international research team in face-to-face and Skype meetings and by e-mail in order to understand contextual issues and to ensure correct data interpretation.

Due to the complex international context of the research project, it was difficult to fully achieve an iterative process⁷⁷ of simultaneous data collection and analysis. Therefore, the data of the individual interviews with patients and family caregivers (Chapter 4) and the group interviews with healthcare professionals (Chapter 7) are possibly not as rich as intended. Furthermore, due to the number of interviews conducted and due to limited time and costs, it was not feasible to literally translate transcripts of the individual patient and family caregiver interviews from Hungary and Germany into English. This was eventually only done for the group interviews with healthcare professionals. Therefore, the analyses of the individual interviews are possibly not as in-depth as intended. Another limitation of this thesis is that it does not highlight differences in the local and national organisation of healthcare systems, therefore, local differences between the integrated palliative care initiatives may be underrepresented. Within the InSup-C project, one single country analysis was conducted⁷⁸ and one integrated palliative initiative in each of the five countries was examined more in-depth⁶¹. These analyses resulted in detailed descriptions of integrated palliative care initiatives and provide more in-depth information in which local issues and priorities in integrated palliative care are highlighted.

Future research should focus on the effects and working elements of an integrated palliative care model, whereby local issues and priorities are investigated as well. It should include the perspectives of patients with both malignant and non-malignant diseases, family caregivers and healthcare professionals and preferably uses a mixed methods design.

Recommendations

Several recommendations on the implementation of integrated palliative care emerge from the discussion of the main findings and methodological considerations. These are presented below and are subdivided into recommendations for clinical practice, research, education and policy.

Clinical practice

1. As part of a patient participation model, motivate patients and their family caregivers early in the patient's illness trajectory to explicitly formulate their needs, wishes and expectations concerning treatment options and their preferences for the organisation of their care trajectory, including how follow-up will be organised.
2. Adopt a person-centred attitude as a health care professional towards your patient and the family caregiver, and facilitate participation by making it explicit early in the palliative care trajectory.
3. Appoint a dedicated healthcare professional who navigates patients and/or family caregivers through the patient's care network and ensure that they know who their first contact person is in case of needs. Moreover, ensure that the patient's general practitioner is continuously involved when care is organised across settings.
4. Provide care with a limited number of trusted healthcare professionals, if possible.
5. Provide interdisciplinary teamwork for complex patients by working towards a shared goal setting with clear delineation of roles, tasks and responsibilities among the healthcare professionals in the patient's care network.
6. Focus on systematically integrated palliative care, for example, by the use of referral pathways, guidelines and systematic (digital) information exchange.
7. Invent standardised information systems that provide access to all healthcare professionals within a patient's care network including the patient and his/her family caregiver.

Research

1. Validate the integrated palliative care definition.
2. In a qualitative study, investigate whether patients prefer having one single key person in their care network and what tasks and responsibilities this person should have.
3. In a qualitative study, examine the perspective of (healthcare) professionals on optimal ways of collaborating in integrated palliative care models, including the best role divisions and key figures.
4. Initiate a mixed-methods study to examine the effects and working elements of an integrated palliative care model. Pilot the implementation of the model and investigate before and after satisfaction of patients with both malignant and non-malignant diseases, family care givers, and healthcare professionals as well as patient's clinical outcomes.

5. Develop indicators for integrated palliative care and its implementation, based on the elements that are crucial for integrated palliative care identified in this study, and validate these indicators.
6. Compare the current implementation of integrated palliative care in a representative sample of palliative care practices in Europe.

Education and awareness

1. Develop dedicated programmes to increase awareness of patients with advanced disease and their family caregivers of their responsibility and empowerment to participate in their treatment trajectory.
2. Integrate palliative care education as a standard part of the curricula of all healthcare professionals (medical and non-medical).
3. Include in the curricula of all (medical and non-medical) professionals related to the care network of the patient a training course on the competencies and skills required for facilitating patient participation and for working in a network environment and cross-setting palliative care teams.
4. Increase the focus on the role of communicator and collaborator in competency frameworks (CanMEDS) underlying curricula for healthcare professionals.
5. Ensure that vision documents for future medical and care professionals include a statement about the importance of developing a professional awareness of the presence of palliative care needs early in the patient's care trajectory.

Policy

1. Incorporate participation of patients and family caregivers in palliative care trajectories as a key aim into organisational strategies.
2. Develop regional and national platforms to collaborate between governments, insurance companies and professional bodies for the development of normative quality frameworks of palliative care stating the meaning and surplus value, as well as how and when to provide this.
3. Increase funding for integrated palliative care, for example, based on the population of patients in need.
4. Redesign funding mechanisms in order to promote integrated palliative care provision (as opposed to siloed care provision).
5. Formulate regulation in such a way that it facilitates the use of standardised (digital) information exchange across a professional network.
6. Organise a quality control cycle of integrated palliative care.

Final conclusion

With this thesis, I explored how integrated care is currently implemented in the clinical practice of preselected palliative care initiatives in several European countries. The studies conducted in this thesis show that from the patient and family caregiver perspective, ensuring continuity of care is essential for promoting integrated palliative care at the micro level. This requires a well-coordinated care network and interdisciplinary teamwork. Integrated palliative care initiatives should also define the appropriate level of participation of patients and family caregivers by making participation explicit, and facilitate a dialogue between the patient, family caregiver, and healthcare professional early in the palliative care trajectory.

From a healthcare professional point of view, the studies conducted in this thesis show that integrated palliative care is currently based on professional networking rather than on systematic implementation in terms of the onset of palliative care, referral pathways, (shared) care responsibilities, and information transfer. In order to enhance integrated palliative care at the meso level, developing a shared proactive palliative care approach is essential. The awareness, knowledge and expertise of healthcare professionals with other backgrounds than palliative care should be increased, and strategies to more systematically implement integrated palliative care should be promoted. These include the use of integrated palliative care guidelines and standardised information systems that are accessible to all healthcare professionals in the patient's care network.

At the macro level, several barriers hamper integrated palliative care. In order to improve integrated palliative care at this level, regulation and funding need to be redesigned to improve the structural support for integrated palliative care programmes as a whole, for patients with malignant and with non-malignant disease in need of palliative care.

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Summary
Samenvatting

Summary

Chapter 1 introduces the rationale underlying this thesis. The number of people in need of palliative care in Europe is expected to increase tremendously in the next decades. This represents a great challenge for future healthcare provision in general, and specifically for palliative care in Europe. Despite increasing recognition of the value of palliative care and because of a number of problems, palliative care in European countries is still sub-optimally organised. First, European countries differ in the extent to which specialised palliative care services have been developed. The availability of these services is often insufficient to meet the needs of all patients in need of palliative care. Second, many patients receive palliative care at a very late stage of their disease, or are even not referred or supported at all. Third, there is a lack of knowledge about the benefits of palliative care and about proactive identification. Fourth, palliative care often focuses on oncology, but patients with other non-malignant diseases may also have palliative care needs. Fifth, the different services that provide palliative care are not integrated. These problems, combined with the growing number of people in need of palliative care, demand an integrated care approach. It is proposed that integrated care will be a useful approach for evaluating current palliative care practices in Europe, and for investigating how integrated palliative care can be promoted. However, in 2013 at the start of the research project on which this thesis is based, there was no blueprint for organising and providing integrated palliative care that could be used to evaluate how to improve the integration of current palliative care practice in Europe. Moreover, an overarching definition of integrated care had yet to be agreed. Therefore, the European Union Seventh Framework Programme project, InSup-C (2013-2016), aimed to investigate this. Parallel to InSup-C, this thesis aims to investigate how integrated care is currently implemented in the clinical practice of a number of preselected palliative care initiatives in several European countries and to provide recommendations for improvement and further implementation.

In **Chapter 2**, we present the research protocol for the prospective multiple embedded case study conducted in the InSup-C project. We describe the procedure for selecting three to five integrated palliative care initiatives in each of the five selected European countries: Belgium, Germany, Hungary, the Netherlands and the United Kingdom. We describe the preselection of palliative care initiatives based on a working definition of integrated palliative care and on a number of selection criteria. From the selected initiatives, we aimed to recruit patients with advanced cancer, chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF), their family caregivers and healthcare professionals. We aimed to follow patients and their family caregivers over a three-month period and to conduct two interviews about their experiences with healthcare provision. We planned one focus group per initiative with healthcare professionals about how integrated palliative care takes shape in daily practice.

Furthermore, we describe a mixed-methods approach for data collection and analysis. We expected that the resulting data would provide important insights into what constitutes best practice as perceived by those using and providing integrated palliative care services, across the five European countries.

In **Chapter 3**, we provide insights into the composition and quality of care networks of patients receiving palliative care in the five European countries, and how these patients perceive integration between healthcare professionals involved in these networks. Furthermore, using a cross-sectional explorative design, we investigated whether the perceived integration is associated with overall satisfaction with care provision. We recruited 157 patients from 22 integrated palliative care initiatives in the five European countries. The majority had cancer and were female, their mean age was 68 years. Approximately one-third of the patients reported contact with a palliative care physician, and almost half reported contact with a palliative care nurse. The quality of relationships with palliative care physicians were rated significantly higher than with other physicians. Compared to patients with cancer, patients with COPD and CHF had significantly lower odds of reporting contact with palliative care physicians, and patients with COPD had significantly lower odds of reporting contact with palliative care nurses. Perceptions of which healthcare professionals or caregivers were mainly responsible for providing palliative care in patient's care networks varied across countries. Perceived integration between healthcare professionals involved in the care network was significantly positively associated with overall satisfaction with care provision. This study suggests that palliative care professionals are valued, but are not always present or recognised as such in patients' care networks. Expert palliative care involvement needs to be made more explicit, especially for non-cancer patients. A single healthcare professional in the care network should support patients in understanding and navigating their palliative care network. Furthermore, we observe that patients seem satisfied with care provision, as long as continuity of care is provided.

In **Chapter 4**, we describe the perception of relational, informational and management continuity of care for those patients and their family caregivers receiving care from several integrated palliative care initiatives in the five European countries. We adopted a longitudinal qualitative study design including two interviews with patients and family caregivers. Twenty-two integrated palliative care initiatives were selected in the five participating countries. We recruited 152 patients with a mean age of 68, the majority were female and had cancer. Additionally, we recruited 92 family caregivers with a mean age of 61, the majority were female. Essential factors were: trusted relationships with a small number of key healthcare professionals to receive tailored care and easy access to help. We report that relational continuity was often deficient, especially with general practitioners. Furthermore, although informational and management continuity between

healthcare professionals in the wider professional community was often lacking, those healthcare professionals involved in the collaborative integrated palliative care initiatives were found to provide consistent and coherent care. In this study, we show that patients and family caregivers are most likely to experience continuity of care from a small number of trusted health care professionals who are available, who provide interdisciplinary care and who regularly transfer information to all health care professionals involved in the patient's care network. Optimising continuity of care requires further integration of integrated palliative care initiatives towards other healthcare professionals involved in the patients' care networks.

Chapter 5 describes how participation is shaped in palliative care trajectories from the perspectives of patients and their family caregivers receiving care from several integrated palliative care initiatives in the Netherlands. The study consisted of a secondary analysis of qualitative interview data. Thirty-one Dutch patients with a mean age of 70 years, predominantly male, and of whom the majority had advanced cancer participated. Moreover, 22 family caregivers participated; they were predominantly female and had a mean age of 62. We identified seven forms of participation. Patients and family caregivers differed in their preference and ability to influence participation. Healthcare professionals did not always offer the opportunity for patients and family caregivers to participate. A person-centred attitude of healthcare professionals and a collaborative and assertive attitude of patients and family caregivers facilitated participation. This study confirms that patients, family caregivers and healthcare professionals have the joint responsibility to ensure that participation is congruent with the wishes of patients and family caregivers and that this is possible within the specific clinical circumstances. However, this study also showed that not all patients with palliative care needs and family caregivers wish or are capable to bear this responsibility. Healthcare professionals have a pivotal role to facilitate a dialogue by making participation explicit early in the illness trajectory. Patients and family caregivers can enhance participation by adopting a collaborative attitude and making their preferences about treatment decisions and expectations about the organisation of their care explicit. In this way, patients, family caregivers and healthcare professionals can enable shared decision making to take place in daily practice.

Chapter 6 presents the results of a study in a preparatory phase of the InSup-C project. We describe the experiences of palliative care pioneers in seven European countries regarding core elements, facilitators and barriers of integrated palliative care implementation, and we provide recommendations for future policy and practice. We used a qualitative interview study design for this. Thirty-four pioneers in primary and secondary palliative care in Belgium, Germany, Hungary, Ireland, the Netherlands, Spain and the United Kingdom were interviewed. We found that integrated palliative care implementation efforts involved a multidisciplinary team approach and cross-sectional

coordination. Informal professional relationships, basic medical education of palliative care, and general awareness were regarded as facilitators of integrated palliative care; barriers included lack of knowledge about when to start palliative care, lack of collaboration, and financial structures. Recommendations for improving access to palliative care included enhancing patient-centeredness, coordination and cooperation, adjusting finance, and the use of digital information exchange. Our findings show that integrated palliative care implementation largely remains provisional and informal due to the lack of standardised treatment pathways, legal frameworks, and financial incentives to support multilevel integration. In order to make integrated palliative care more available and accessible, palliative care education as well as legal and financial support within national healthcare systems needs to be improved.

Chapter 7 describes how integrated palliative care takes shape in practice across four key domains of integrated care (content of care, patient flow, information logistics, and availability of (human) resources and material), from the perspectives of healthcare professionals involved in several integrated palliative care initiatives in the five European countries. We used a qualitative group interview design, holding 19 group interviews with 142 healthcare professionals. The majority of the participants were nurses and physicians. The dominant strategy for fostering integrated palliative care was building core teams of palliative care specialists and extended professional networks based on personal relationships, shared norms, values and mutual trust. Barriers to providing integrated palliative care with healthcare professionals in the wider professional community were a lack of a shared proactive interdisciplinary palliative care approach, and the unfamiliarity of healthcare professionals in the wider professional community with palliative care professionals or services. We report that achieving better palliative care integration into regular healthcare, and convincing the wider professional community will be a difficult task demanding both time and effort. We suggest that palliative care should be better integrated into education programmes, referral pathways and guidelines, and information exchange. External authority by policy makers, insurance companies and professional bodies will be needed to support integrated palliative care practices across settings.

Chapter 8 presents and discusses the main findings of this thesis in light of relevant and recent literature. This thesis shows that from the patient and family caregiver perspective, ensuring continuity of care is essential for promoting integrated palliative care implementation at a micro-level. This requires a well-coordinated care network, interdisciplinary teamwork, and defining the appropriate level of participation of patients and family caregivers. From a healthcare professional point of view, integrated palliative care is currently based on professional networking rather than on systematic implementation in terms of the onset of palliative care, referral pathways, (shared) care responsibilities, and information transfer. In order to enhance integrated palliative care at the meso-level,

developing a shared proactive palliative care approach is essential. The awareness, knowledge and expertise of healthcare professionals with other backgrounds than palliative care should be increased, and strategies to more systematically implement integrated palliative care should be promoted. These include the use of integrated palliative care guidelines and standardised (digital) information systems that are accessible to all healthcare professionals in the patient's care network. In order to improve integrated palliative care at the macro-level, regulation and funding need to be redesigned to improve the structural support for integrated palliative care programmes for patients with oncologic and non-oncologic diseases in need of palliative care. This thesis concludes with a number of recommendations for clinical practice, research, policy and education.

Samenvatting

Hoofdstuk 1 beschrijft de aanleiding voor dit proefschrift. Het aantal mensen met behoefte aan palliatieve zorg in Europa neemt naar verwachting de komende decennia fors toe. Deze ontwikkeling vormt een grote uitdaging voor de toekomstige zorgverlening in zijn algemeenheid en specifiek voor palliatieve zorg in Europa. Een aantal problemen laten echter zien dat de organisatie van palliatieve zorg in Europa nog suboptimaal is. Er zijn bijvoorbeeld grote verschillen tussen de verschillende Europese landen in de beschikbaarheid van gespecialiseerde palliatieve zorg. Deze beschikbaarheid voldoet lang niet altijd aan de vraag van mensen met een behoefte aan palliatieve zorg. Daarnaast ontvangen veel patiënten pas laat in hun ziekteverloop palliatieve zorg of ontvangen zij helemaal geen palliatieve zorg. Ook is er een gebrek aan kennis en consensus over de meerwaarde van palliatieve zorg en over proactieve identificatie. Bovendien is palliatieve zorg nog grotendeels gericht op patiënten in een oncologisch traject, terwijl mensen met niet-oncologische aandoeningen ook behoefte kunnen hebben aan palliatieve zorg. Ten slotte zijn de diverse diensten en organisaties die palliatieve zorg verlenen vaak niet op elkaar afgestemd. Deze problemen en de groeiende populatie van mensen met behoefte aan palliatieve zorg vragen om een geïntegreerde zorg benadering. Een geïntegreerde zorg benadering kan behulpzaam zijn bij het evalueren van huidige palliatieve zorg praktijken in Europa en bij het onderzoeken van mogelijke verbeteringen. Echter, in 2013 bij de start van het onderzoeksproject waarop dit proefschrift is gebaseerd, waren er geen welomschreven 'goede voorbeelden' voor het organiseren en verlenen van geïntegreerde palliatieve zorg die gebruikt konden worden om de huidige palliatieve zorg praktijk in Europa te verbeteren. Ook was er geen breed gedragen definitie van geïntegreerde palliatieve zorg. Daarom stelde InSup-C (2013-2016), een onderzoeksproject gesubsidieerd vanuit het zevende kaderprogramma van de Europese Unie, zich ten doel om dit te onderzoeken. Parallel aan InSup-C is het doel van dit proefschrift te onderzoeken hoe geïntegreerde palliatieve zorg momenteel vorm krijgt in de klinische praktijk van een aantal geselecteerde palliatieve zorg initiatieven in vijf verschillende Europese landen en aanbevelingen te geven voor verbeteringen en verdere implementatie.

In **Hoofdstuk 2** presenteren we het protocol van een prospectieve meervoudige case studie van het InSup-C project. We beschrijven de procedure voor het selecteren van drie tot vijf geïntegreerde palliatieve zorg initiatieven in de vijf geselecteerde Europese landen: België, Duitsland, Hongarije, Nederland en het Verenigd Koninkrijk. We wilden palliatieve zorg initiatieven selecteren op basis van een werkdefinitie van geïntegreerde palliatieve zorg en een aantal selectiecriteria. We beoogden vanuit de geselecteerde initiatieven patiënten met gevorderde kanker, chronische obstructieve longziekten (COPD) en chronisch hartfalen (CHF), hun mantelzorgers en zorgverleners te werven. We planden patiënten en mantelzorgers gedurende drie maanden te volgen en twee interviews met

hen te houden over hun ervaringen met de zorgverlening. Ook planden we per initiatief één focusgroep met professionele zorgverleners te houden over hoe zij geïntegreerde palliatieve zorg in de dagelijkse praktijk implementeren. Verder beschrijven we een gecombineerde methoden benadering voor de dataverzameling en analyse. We verwachtten dat de uitkomsten van deze studie belangrijke inzichten zouden bieden over 'best practices' van geïntegreerde palliatieve zorg in de vijf Europese landen zowel vanuit het perspectief van zorgverleners die geïntegreerde palliatieve zorg diensten verlenen als de patiënten en mantelzorgers die er gebruik van maken.

In **Hoofdstuk 3** geven we inzicht in de samenstelling en kwaliteit van zorgnetwerken van patiënten die palliatieve zorg ontvangen in de vijf geselecteerde Europese landen en in hoe deze patiënten de afstemming ervaren tussen zorgverleners die betrokken zijn bij deze zorgnetwerken. We voerden een cross-sectionele explorerende studie uit. Deelnemers bestonden uit 157 patiënten die waren geworven vanuit 22 geïntegreerde palliatieve zorg initiatieven in de vijf Europese landen. De gemiddelde leeftijd was 68 jaar en de meerderheid had kanker en was vrouw. Ongeveer een derde van de patiënten gaf aan contact te hebben met een arts gespecialiseerd in palliatieve zorg en bijna de helft van de patiënten gaf aan contact te hebben met een verpleegkundige gespecialiseerd in palliatieve zorg. De kwaliteit van relaties met artsen gespecialiseerd in palliatieve zorg werd significant beter gescoord dan die van relaties met andere artsen. Vergeleken met patiënten met kanker hadden patiënten met COPD en CHF een significant lagere kans op het hebben van contact met artsen gespecialiseerd in de palliatieve zorg (wat betreft de kans gaat het hier in statistische zin om de kansverhouding; de odds). Ook hadden patiënten met COPD een significant lagere kans op het hebben van contact met verpleegkundigen gespecialiseerd in palliatieve zorg. Welke zorgverleners, volgens patiënten, de regie hadden in het zorgnetwerk verschilde per land. Ervaren afstemming tussen zorgverleners in het zorgnetwerk hing significant positief samen met algemene tevredenheid over de zorgverlening. Deze studie concludeert dat palliatieve zorgverleners gewaardeerd worden maar vaak niet aanwezig zijn of als zodanig herkend worden in zorgnetwerken van patiënten. De betrokkenheid van palliatieve zorgverleners moet explicieter gemaakt worden, in het bijzonder voor niet-kanker patiënten. Een zorgverlener in het zorgnetwerk moet patiënten ondersteunen in het begrijpen van hun palliatieve zorgnetwerk, zodat ze weten wie de regie heeft en bij welke zorgverlener ze moeten zijn wanneer ze iets nodig hebben. Verder concluderen we dat patiënten tevreden zijn met de zorgverlening mits er continuïteit van zorg is.

In **Hoofdstuk 4** onderzoeken we hoe continuïteit van relaties, informatie en coördinatie wordt ervaren door patiënten met een gevorderde ziekte en hun mantelzorgers die zorg ontvangen van verschillende geïntegreerde palliatieve zorg initiatieven in de vijf Europese landen. We voerden een longitudinale kwalitatieve studie uit waarin we steeds twee

interviews hielden met patiënten en mantelzorgers. We selecteerden 22 geïntegreerde palliatieve zorg initiatieven in de vijf deelnemende Europese landen. Deelnemers bestonden uit 152 patiënten van wie de meerderheid kanker had, vrouw was en een gemiddelde leeftijd van 68 jaar had. Daarnaast bestonden de deelnemers uit 92 mantelzorgers van wie de meerderheid vrouw was en een gemiddelde leeftijd van 61 jaar had. Patiënten en mantelzorgers gaven aan dat het essentieel voor hen is dat zij een vertrouwelijke relatie hebben met een klein aantal centrale zorgverleners. Dit maakte het voor patiënten mogelijk op maat gemaakte zorg te ontvangen en gemakkelijk hulp te vragen. Hoewel continuïteit van informatie en coördinatie bij zorgverleners in het bredere professionele netwerk vaak als onvoldoende werd ervaren, werd de zorgverlening van zorgverleners die betrokken waren bij de samenwerkende geïntegreerde palliatieve zorg initiatieven vaak geassocieerd met consistente en coherente zorg. Deze studie laat zien dat patiënten en mantelzorgers continuïteit van zorg ervaren wanneer zij een klein aantal vertrouwde zorgverleners om zich heen hebben die laagdrempelig beschikbaar zijn, die interdisciplinaire zorg verlenen en regelmatig informatie overdragen naar alle zorgverleners die bij het zorgnetwerk van de patiënt betrokken zijn. Om continuïteit van zorg te optimaliseren dienen geïntegreerde palliatieve zorg initiatieven beter te integreren met andere zorgverleners die bij het zorgnetwerk van de patiënt betrokken zijn.

Hoofdstuk 5 beschrijft hoe participatie van patiënten en mantelzorgers vorm krijgt in verschillende palliatieve zorg trajecten, gezien vanuit de perspectieven van de betreffende patiënten en hun mantelzorgers. De studie betrof een secundaire analyse van kwalitatieve interview data. De deelnemers waren 31 Nederlandse patiënten met een gemiddelde leeftijd van 70 jaar, waarvan de meerderheid man was en gevorderde kanker had. Verder deden 22 mantelzorgers mee die een gemiddelde leeftijd hadden van 62 jaar en van wie de meerderheid vrouw was. We identificeerden zeven vormen van participatie. Patiënten en mantelzorgers verschilden in de voorkeuren die zij hadden en in de mate waarin zij in staat waren om participatie te beïnvloeden. Zorgverleners boden patiënten en mantelzorgers niet altijd de mogelijkheid om te participeren. Een persoonsgerichte houding van zorgverleners en een samenwerkende en assertieve houding van patiënten en mantelzorgers faciliteerden participatie. Deze studie bevestigt enerzijds dat patiënten, mantelzorgers en zorgverleners de gezamenlijke verantwoordelijkheid hebben ervoor te zorgen dat participatie voldoet aan de voorkeuren van patiënten en mantelzorgers en ook mogelijk is binnen de specifieke klinische omstandigheden. Anderzijds laat deze studie zien dat niet alle patiënten met palliatieve zorg behoeften en hun mantelzorgers in staat zijn om deze verantwoordelijkheid te dragen. Zorgverleners hebben de cruciale rol om al vroeg in het ziekte-traject een dialoog over participatie te starten met de patiënt en diens naaste(n). Patiënten en hun mantelzorgers op hun beurt kunnen hun participatie vergroten door open te staan voor samenwerking en hun voorkeuren en verwachtingen voor de behandeling en organisatie van hun zorg expliciet te bespreken. Op deze wijze krijgt

‘shared decision making’ betekenis in de dagelijkse omgang tussen zorgverleners, patiënt en naaste(n).

Hoofdstuk 6 presenteert de resultaten van een studie die uitgevoerd werd in een opstartfase van het InSup-C project. We beschrijven de perspectieven van pioniers in de palliatieve zorg in zeven Europese landen op kernelementen van geïntegreerde palliatieve zorg inclusief bevorderende en belemmerende factoren en we geven aanbevelingen voor toekomstig beleid en de zorgpraktijk van alle dag. We voerden een kwalitatieve studie uit. We hielden interviews met 34 pioniers in eerste –en tweedelijns palliatieve zorg in België, Duitsland, Hongarije, Ierland, Nederland, Spanje en het Verenigd Koninkrijk. Strategieën voor het implementeren van geïntegreerde palliatieve zorg waren een multidisciplinair team en transmurale coördinatie. Informele professionele relaties, palliatieve zorg onderwijs in de basiscurricula van medische opleidingen en algemene bewustwording werden beschouwd als bevorderende factoren voor geïntegreerde palliatieve zorg. Beperkende factoren waren een gebrek aan kennis over het optimale startmoment van palliatieve zorg, een gebrek aan samenwerking en de beperking door de huidige financiële structuren. Aanbevelingen voor het verbeteren van de toegang tot palliatieve zorg waren een grotere patiëntgerichtheid, meer coördinatie en samenwerking, passende financiering en het gebruik van digitale informatiesystemen. Onze bevindingen laten zien dat de implementatie van geïntegreerde palliatieve zorg voornamelijk basaal en informeel is vanwege het gebrek aan gestandaardiseerde zorgpaden, wettelijke kaders en financiële prikkels die integratie van palliatieve zorg op meerdere niveaus zouden kunnen ondersteunen. Om betere integratie van palliatieve zorg mogelijk te maken moeten nationale gezondheidssystemen meer ruimte bieden voor zowel onderwijs in palliatieve zorg als regelgeving en financiële ondersteuning voor palliatieve zorg.

Hoofdstuk 7 beschrijft hoe geïntegreerde palliatieve zorg in de praktijk vorm krijgt in vier centrale domeinen van geïntegreerde zorg (inhoud van zorg, patiëntenlogistiek, informatielogistiek, beschikbaarheid van personeel en materiaal) vanuit de perspectieven van zorgverleners die betrokken zijn bij verschillende geïntegreerde palliatieve zorg initiatieven in de vijf Europese landen. We voerden een kwalitatieve studie uit waarbij in totaal 142 zorgverleners aan negentien groepsinterviews deelnamen. De meerderheid van de deelnemers bestond uit verpleegkundigen en artsen. De voornaamste strategie om geïntegreerde palliatieve zorg te stimuleren was het bouwen van kernteams van palliatieve zorg specialisten en het uitbreiden van professionele netwerken door middel van persoonlijke relaties, gedeelde normen en waarden en onderling vertrouwen. Beperkende factoren voor het realiseren van geïntegreerde palliatieve zorg onder zorgverleners in het bredere professionele netwerk waren de afwezigheid van een gedeelde proactieve interdisciplinaire palliatieve zorg visie en de onbekendheid van zorgverleners in het bredere professionele netwerk met palliatieve zorgverleners en hun dienstverlening. We

constateren dat niet alleen het bereiken van een betere integratie van palliatieve zorg in de reguliere gezondheidszorg, maar ook het overtuigen van zorgverleners in het bredere professionele netwerk van de meerwaarde van palliatieve zorg, een ingewikkelde taak is die tijd en inspanning vergt. We raden aan om een geïntegreerde aanpak van palliatieve zorg te vergroten door middel van onderwijs, verwijspaden, richtlijnen en om systemen voor informatieoverdracht toegankelijker te maken. Verder zal externe invloed van beleidsmakers, verzekeringsmaatschappijen en beroepsverenigingen nodig zijn voor het ondersteunen van geïntegreerde palliatieve zorg over de grenzen van organisaties heen.

Hoofdstuk 8 presenteert de belangrijkste bevindingen van dit proefschrift en bespreekt deze in het licht van relevante en recente literatuur. Dit proefschrift laat zien dat vanuit het perspectief van de patiënt en mantelzorger continuïteit van zorg essentieel is voor het verbeteren van de implementatie van geïntegreerde palliatieve zorg op microniveau. Dit vraagt om een goed gecoördineerd zorgnetwerk, interdisciplinaire samenwerking en het bepalen van het juiste participatieniveau van patiënten en mantelzorgers. Vanuit het perspectief van de zorgverlener is geïntegreerde palliatieve zorg momenteel gebaseerd op uitbreiden van professionele netwerken in plaats van op systematische implementatie van palliatieve zorg, verwijspaden en (het delen van) verantwoordelijkheden voor de zorg en informatieoverdracht. Om geïntegreerde palliatieve zorg op het mesoniveau te versterken is het ontwikkelen van een gedeelde visie op proactieve palliatieve zorg essentieel. Ook dienen bewustwording, kennis en deskundigheid van zorgverleners met andere achtergronden dan palliatieve zorg te worden vergroot en dienen strategieën om geïntegreerde palliatieve zorg systematischer te implementeren te worden gestimuleerd. Dit betekent onder andere de integratie van palliatieve zorg in richtlijnen en gestandaardiseerde (digitale) informatie systemen die toegankelijk zijn voor alle zorgverleners in het zorgnetwerk van de patiënt. Voor het verbeteren van geïntegreerde palliatieve zorg op macroniveau dient regelgeving en financiering te worden heringericht, zodat geïntegreerde palliatieve zorg programma's voor zowel oncologische als niet-oncologische patiënten met behoefte aan palliatieve zorg structureel ondersteund kunnen worden. Dit proefschrift wordt afgesloten met een aantal aanbevelingen voor de klinische praktijk, onderzoek, beleid en onderwijs.



Dankwoord | words of gratitude
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Appendices

Dankwoord / words of gratitude

Wat ben ik blij dat ik nu na een zware klim naar boven op de top van de berg sta en uitkijk over de laatste dingen die er nog moeten gebeuren om mijn proefschrift af te ronden. Heerlijk dat ik nu op het punt sta mijn dankwoord te schrijven! Op deze plek wil ik een aantal mensen bedanken die op een bepaalde manier hebben bijgedragen aan dit proefschrift.

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Curriculum Vitae

Marlieke (Margaretha Elisabeth) van der Eerden was born on 3 January 1986 in Boxtel. As a young girl, she dreamt of becoming a plastic surgeon and helping patients with facial deformities in Africa. In 2004, Marlieke graduated from secondary school (CSG Willem van Oranje, Oud-Beijerland). Unfortunately, she was unable to start immediately due to the university entrance system in the Netherlands. So she enrolled in the Biomedical Sciences programme at the University of Antwerp, Belgium, hoping to be able to move into medicine from there.

In 2005, Marlieke completed her initial Biomedical Sciences entrance year, however was not granted access to her desired medical study. As she had also become interested in foreign cultures, human behaviour and travelling abroad, she started studying Social and Cultural Anthropology at the VU University Amsterdam. As part of the programme, she spent 5 months in Brazil studying at the Universidade Federal de Minas Gerais, Belo Horizonte. In 2008, she graduated with a Bachelor's degree in Social and Cultural Anthropology.

While studying, Marlieke had joined the Board of the Navigators Student Association in Amsterdam. She realised that she was still passionate about healthcare, with an added interest in organisation and management. So in 2009, she started a Master's degree in Health Sciences with a specialisation in International Public Health, at the VU University Amsterdam. She travelled to Cambodia for her Master's thesis to investigate access to healthcare and stigma among people affected by leprosy.

After being awarded her Master's degree in Health Sciences, she started work as a DBC (Diagnosis Treatment Combination) Advisor at the Medical Center Haaglanden in 2011. However, as she was more interested in improving the quality and organisation of healthcare than in the administrative part of it, in 2013 she started her PhD at the Radboud University Medical Center on integrated palliative care. In the past five years, she has enjoyed investigating integrated palliative care together with her colleagues working on the European InSup-C project.

While completing her PhD, Marlieke married Jan-Willem den Herder, and on 19 August 2017 she gave birth to her son Thomas. Currently, she works as a Quality and Safety Advisor at the Canisius-Wilhelmina hospital in Nijmegen, the Netherlands, where she builds on her strong knowledge base, making her contribution to the continuous improvement of healthcare.

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Den Herder-van der Eerden M, Hasselaar J, Vissers K, Groot M. Patient and family caregiver perspectives on their participation in palliative care: a qualitative study. *Submitted*

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Appendix 1, Chapter 2 en 3: Caregiver network analysis questionnaire

1. Which caregivers do you have contact with to receive daily care, advice about your disease, medical treatment, psychological support, finances, etc.?

Family/informal caregiver	<input type="checkbox"/> Yes	<input type="checkbox"/> No
GP	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Home care worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Nurse	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Medical specialist	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Allied Health Professional	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Social Worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Faith leader	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Psychological support worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Hospice worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Other, ...	<input type="checkbox"/> Yes	<input type="checkbox"/> No

2. For those with whom you have contact, how often and how do you have contact?

Family/informal caregiver	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
GP	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Home care worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Nurse	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Medical specialist	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Physiotherapist	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail

Social Worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Faith leader	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Psychological support worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Hospice worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Other, ...	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less <input type="checkbox"/> Often
	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail

3. For those with whom you have contact, how would you rate your relationship with this caregiver?

Family/informal caregiver	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
GP	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Home care worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Nurse	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Medical specialist	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Physiotherapist	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Social Worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Faith leader	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Psychological support worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Hospice worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Other, ...	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor

4. For those with whom you have contact, how would you rate care that you receive from these caregiver?

Family/informal caregiver	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
GP	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Home care worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Nurse	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Medical specialist	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor

Physiotherapist	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Social Worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Faith leader	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Psychological support worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Hospice worker	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor
Other, ...	<input type="checkbox"/> Excellent <input type="checkbox"/> Very Good <input type="checkbox"/> Good <input type="checkbox"/> Reasonable <input type="checkbox"/> Poor

Statements and questions about collaboration between caregivers from whom you receive care:

- These caregivers appear to work together very well.**
☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree
- The care given by these caregivers appears to be well-connected.**
☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree
- These caregivers pass on information to each other well.**
☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree
- These caregivers always know very well what the other caregivers have done.**
☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree
- Sometimes I perceive friction between caregivers.**
☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree
- Who, do you think, is the main responsible caregiver of all caregivers you receive care from?** (i.e. the person(s) who decide(s) how your care is being organised)
- Is there anything missing from the care you receive and who do you think should be providing it?** (Which persons/organisations do you miss and why?)
- In your opinion, might there be too many caregivers from whom you receive care?** (Which persons/organisations may be redundant and why?)

Appendix 2, Chapter 4: Interview protocol - Baseline interview patient

What to bring?

- big white paper
- pens for making notes and for marking the collaboration between caregiver in theme 2.
- post-its
- audio-recorder + extra batteries
- photo camera + extra batteries
- note book
- participant information sheet (PIS)
- demographic questions
- social network analysis (SNA) questionnaire

Introduction

1. Who is the interviewer?

- Who you are and where you are from.

2. What can I and/or can I not do for you?

- As a researcher you are here to ask questions in light of the study.
- You are not (here) a(s) caregiver and therefore cannot give advice about aspects related to the patient's illness. (If necessary you can instruct/support the patient to contact his/her caregiver).
- You have about 1.5 hours. Does the patient have any appointments after this interview which you should take into account?
- Whenever the patient is not feeling well, (s)he can decide to interrupt or stop the interview at any moment.
- Explain what the patient can expect during this contact moment: (1) general introduction about aim and procedures of entire study; 2) first interview (comprising demographic data, SNA and the interview itself).

3. Participant information sheet (reiteration)

The following items of the PIS should be reiterated:

- Aims of the study (see PIS)
- Study procedures/follow-up (see PIS)
- Reason why you want to interview the patient (see PIS)
- Reason why personal information of the patient is necessary (importance of seeing the results in the right context).
- You are interested in the personal view of the patient and that there are no (right or) wrong answers.

- Ask permission to audio-record the interview (see PIS) and make pictures.
Explain why this is necessary.
- The information the patient provides is confidential (see PIS).
(You could mention that all quotes / details that may be used in presentations or papers do not use names and initials etc. of patients (= kept confidential).
- Explain why will you make notes during the interview.

4. What are the aims and procedure of this baseline interview?

- a) To explore how the patient experiences the care and support (s)he receives from caregivers for his/her problems and needs.
 - b) To know more about how (s)he experiences contact with caregivers and collaboration between caregivers.
- Before the actual interview starts, you will ask some personal, demographic questions. Secondly you will conduct a social network analysis (in order to get a picture of the caregivers that are around the patient to give care or support). Then you will start the interview in which you will explore the answers given in the social network analysis. You will use cards to structure the interview questions. In the interview you will ask various questions about these cards. Invite the patient to think out loud why (s)he is placing the cards in a particular way.

5. Assess demographic data

[Be aware of problems / needs the patient may raise here and during SNA and make notes of these. Come back to these during the discussion of problems/needs in the interview if the patient does not mention these then].

6. Conduct the Social Network Analysis (SNA)

[Write down the caregivers the patient has contact with on cards (use SNA). Also make a card with 'patient' on it. Place these cards in front of the patient]. Before you are going to use these caregiver cards, you will ask some questions about problems and needs. Explain that the interview will start now.

➔ **Start audiotape**

The interview

Theme 1: problems and needs

Introduce the theme 'problems and needs'. Experiences of patients with provision of care and contacts with caregivers, often have to do with what they expect of it, whether it meets their expectations and their problems and needs. Therefore you would like to explore illness related problems/needs the patient may experience. When you have a picture of the patients' problems and needs, you will explore how the patient experiences his/her contact with caregivers and the collaboration between caregivers. [Explain the difference between problems and needs].

Problems

Introduce the questions about problems: e.g. "given that your are ill, I could imagine that you experience various problems..."

Questions	Probing opportunities
Q1: Can you tell which problems you currently encounter? [Write down each problem on a card]	<div>1. <i>In case the patient does not know how to express problems, you can ask for problems in the following domains:</i><ul style="list-style-type: none">- Daily activities- Problems with your body- Problems with(in) your mind- Administrative (and financial) matters- Family/friends matters- Receiving support (what or who?)- Independency- Need for information- The care you receive</div> <div>2. <i>When patients only mentions a vague term, e.g. 'fear':</i><ul style="list-style-type: none">- What are you scared for?- Can you tell about a situation in which you were scared?- What do you do when you are scared?- What does fear do with you?</div> <div>3. <i>In case the patient does not experience any problems, you can ask:</i> <i>"Which problems (related to the illness) you experienced in the past are currently supported?"</i></div>
Q2: Can you place these problem cards in order of importance to you? <i>(NB: This question was removed in agreement with the research group, as it was too similar with question Q3).</i>	

Q3: Can you place these problems cards in order of priority (which problems need to be resolved by a caregiver first of all)? [Take a picture of the problems in order of priority]	- Explore why the patient chooses this particular order.
Summarise	

Needs

After discussing the problems, you will now ask the same questions for needs.

Questions	Probing opportunities
Q4: Can you tell which needs you experience: i.e. issues for which you need support/attention? (write down each need on a card).	<p>When e.g. 'being in control' is mentioned:</p> <ul style="list-style-type: none"> - What happens when you are in control? - Can you tell about a situation in which you were in control? - What does it mean for you to be in control?
Q5: Can you place these cards in order of priority (which of these needs need to be resolved by a caregiver first of all)? [Take a picture of the needs in order of priority]	<ul style="list-style-type: none"> - Explore why the patient chooses this particular order.
Summarise	

Theme 2: relationships and communication with and between caregivers

Relations between the patient and caregivers

Explain that you would like to explore the contact between the patient and caregivers now.

You are going to use the cards with caregivers on it. Place the 'patient' card in the middle.

Questions	Probing opportunities
Step 1: With which caregivers do you have more or less frequent contact? (refer to the SNA) [Let the patient place the caregivers with whom (s)he has most frequent contact closest to the 'patient' card and those with whom (s) he has the least frequent contact further away from the 'patient' card] [Take a picture of the frequency of contacts in the care network]	
Step 2: What do these caregivers do when you have contact with them?	- What kind of care or support is provided?
Step 3: Which caregivers are most important to you? [Let the patient place the caregivers which are more important for him/her closer to the patient card and those who are less important further away]. [Take a picture showing the caregivers that are more and less important for the patient]	<p>You can think of importance in two dimensions:</p> <ul style="list-style-type: none"> - Relational dimension e.g. caregiver shows acknowledgement (has emphatic attitude); shows commitment; shows involvement - Giving dimension e.g. caregiver gives medication/ treatment; gives information (by being clear/honest about the patient's current position and/or prognosis); gives hope
Step 4: Why are these caregivers important to you?	
Step 5: For which of the 3 highest priority problems and needs (Q3 and Q5) support is currently provided by these caregivers? [Place the card with the problems/needs on the particular caregiver. If there are more caregivers that treat one problem, make more cards with the same problem on it].	
Step 6: Would you like to mention an additional priority problem/need for which you currently receive support, that you did not mention in step 5? [Take picture showing the 3 (or 4) highest priority problems/needs that are currently supported by caregivers and the problems/needs that remain]	- Explore why this additional problem/need is mentioned.
Summarise	

Collaboration between caregivers

Explain that after discussing the patient’s contact with several caregivers, you would like to focus on the collaboration between caregivers. Let the patient draw lines between caregivers using markers.

Questions	Probing opportunities
Q11: Who, do you think, works together in the care network in front of you. How do you notice this?	- Explore whether the collaboration is focused on care for the patient or on care for the family caregiver.
[Take a picture showing collaboration between caregivers in the network]	
Q12: What is the importance for you, that these caregivers work together? Why?	
Q13: Who, do you think, should work together but does not do this now? Why?	- Explore why they do not work together now.
[Take a picture showing caregivers in the network that should work together]	
Summarise	
Is there something you would like to say or add? Do you have any questions?	

Closing

Thank the patient for his/her time and if applicable, give present.

Explain what will happen from now on:

- Keep diary weekly
- Complete questionnaires monthly
- That you will remind the patient (by telephone?) to fill in the diary and questionnaires.
- The results will be available at the end of 2015/early 2016. In the meantime patient can visit website www.insup-c.eu.
- Give your contact details in case the patient wishes to contact you or has questions.

➔ Stop audiotape

Appendix 3, Chapter 7:
A group interview with professionals – InSup-C

Who are we going to invite?

- For discussion: various healthcare professionals working in/associated to one particular initiative (inclusion at least partly motivated by patient interviews and SNA's)

Physical requirements for conducting the interview

- You will need a space that facilitates undisturbed and calm conversations
- The room has to be big enough for +/- 8 people. You arrange the room so as to stimulate interaction (circle; rectangle)
- The room should have a pleasant climate for 90 minutes
- Think about conducting the interview with an independent conversation leader (if available) and one researcher. At least, make sure that the researcher has time/opportunities to bring in his/her particular knowledge about the initiatives.
- What to bring? White board/flip board; markers; audio recorder suited to record group conversations, need a separate, multi directional microphone

This interview guide assumes a 90 minute group session

Preparation

- Consider using PowerPoint – or some other visual method – to display the main questions in each of the steps as prompts for the discussion
- Ask participants to complete the demographic sheet in as much detail as they wish

To start: the formal part

- To give everybody a warm welcome
- Explain the aim of the study
- Explain the aim of the group interview:
“in this interview we would like to explore how you experience, or have experienced working with this/being part of this integrated palliative care initiative All of you have somehow been involved in patient care through this initiative, and we would like you to discuss how the multidisciplinary collaboration contributed or, perhaps, impeded high-quality care for the patient. In more general terms: “How is the initiative doing so far?”
- We are especially interested in what goes well in delivering integrated palliative care in the initiative. What are the things they are proud of? Why does that succeed; what can others learn from that?
- We will pose initial questions and/or present propositions to start up the discussion. Please feel free to share your opinions and feelings or to respond to one of the other

members of this group. The conversations will be audio-recorded and transcribed. Both the audio files and the transcripts will be kept confidential. Only the researchers have access to the research material. All quotes used in research papers or presentations will be anonymised.

Ground rules

It is useful to have these ground rules on a slide or on flip chart paper for you (and they) to refer to

- Ask participants to switch off phones (or switch to silent if they need to remain available)
- Suggest that if participants need to leave the room (or leave the session) that they do so quietly
- Ask participants to respect confidentiality i.e. not to repeat or talk about what is said in the group interview to others (this is important as many of the people present will continue to work together and it 'frees up' people to be more honest in the discussion)
- Ask participants to treat each other's comments and opinions with respect. It is possible to disagree – but to do so respectfully
- Remind people that the conversation will be recorded and transcribed, so it is important not to speak over each other or at the same time. Tell them that you may remind them of this again if the discussion gets enthusiastic!
- **Before starting the interview, please make an introduction round.**

The logic behind the interview

To prepare for the group interview, we suggest that you and the independent chair/conversation leader (re-)read the presentation of Jeroen van Wijngaarden, January 20, 2015, and the article 'Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care' by Valentijn et al. to (re)gain a feel for the dimensions of integrated care. You will need this knowledge of integrated care to check, during the interview, whether participants' answers cover all important dimensions of integrated care. In other words, this knowledge will help you to ask critical probing questions in case of one-dimensional answers.

Also look at the interview material with the patients. Try to identify what they particularly appreciate in this initiative. Present these examples during the group interview to try to understand what is required to get these results.

The interview process

We will invite the group to 'think out loud' about the questions and statements. If a second researcher is present (or a researcher next to the conversation leader), he/she can write key words/phrases on the whiteboard/flipchart so that these may be referred to during the interview: to note links and connections and/or to explore aspects that may have received scant attention.

(While participants are discussing the answers, please stay alert to pick up cues with which you can further the discussion)

Step 1: Description of the integrated palliative care initiative – the patients

- a. Please describe a situation in which you believe a patient received good quality integrated palliative care. Why did that go so well?
- b. What are in general the things that you are proud of in your initiative? Why does that work so well and what can others learn from that?
- c. Please describe a situation in which you believe a patient received poor quality integrated palliative care. Why did that happen and what can we learn from that?
- d. What makes the difference between good and bad integrated palliative care?
- e. What are the particular 'types' or characteristics of patients for whom integrated palliative care works best/worst?
- f. What difference – if any – does the particular condition (cancer, COPD, CHF) make?
- g. Ideally, at what moment is a patient referred to/admitted into the integrated palliative care initiative?
- h. Which professionals are involved with patients at what time(s)?

*Try to stimulate discussion as much as possible: ask clarifying questions; ask participants to respond to one another; ask if participants experiences are similar or different. Mentioned below are a few propositions that **could** help stimulate the discussion as well (these propositions contain elements that are available for probing. E.g., the 'how-question'):*

1. Please respond: "Well integrated palliative care covers appropriate assessment at first appointment and on-going review during the disease trajectory."
2. Please respond: "Well integrated palliative care guarantees timely access to services based on patient/family needs and wishes."
3. Please respond: "Well integrated palliative care supports choice and personalized care using tools (where appropriate) such as: advance care plans; advance decision to refuse treatment; do not attempt cardio-pulmonary resuscitation (DNAR) orders; preferred priorities of care etc."

Step 2: Description of the integrated palliative care initiative – communication and information

In this second step, we focus on communication and the sharing of information. Let participants react to the following questions:

1. How does the initiative provide the right information, at the right time?
 - a. For patients?
 - b. For family caregivers?
 - c. For professionals?

- d. What is “the right information, at the right time” (at least)?
- e. How do information needs differ – if at all – between the conditions this study is concerned with (cancer, COPD, CHF)?
2. What communication channels are used by professionals?
3. What are some of the enablers and barriers to good communication?
 - a. Between professionals and patients/carers?
 - i. How are patients included in care planning and decision making?
 - ii. How are family caregivers included in care planning and decision making?
 - b. Between professionals?
 - i. How are changes to individual care plans made and communicated to all members of the wider care team
 - c. Between agencies in the initiative?
 - d. With other agencies not connected to the initiative **(mentioned in the patient/carer interviews)?**

*Mentioned below are a few propositions that **could** help stimulate the discussion as well (these propositions contain elements that are available for probing. E.g., the ‘how-question’):*

1. Please respond: “Well integrated palliative care facilitates regular and open conversations about end of life needs, patient values, and patient preferences as well as advanced care planning.” + Whether and how should this knowledge be shared with other caregivers.
2. Please respond: “Well integrated palliative care produces information/facilitates appointments about treatment and care during the disease trajectory and towards the end of life – including where the person wishes to die and what services are available at that time and for bereaved people”.

You could offer a BREAK to participants if appropriate.

Step 3: Description of the integrated palliative care initiative – the content of care

In this third step, we will focus on the content and continuity of care. Let participants react to the following questions.

- a. What makes or who ensures that the patient receives the right level of palliative care at the right moment in the disease trajectory?
- b. How is the continuity of care attended to and delivered within the initiative/across care givers and organisations?
- c. How is palliative care delivery aligned with the patients’ and family caregivers’ wishes?
- d. How is ‘holistic patient assessment’ assured? I.e. that all aspects of care are covered: physical, psychological, spiritual and social?
- e. What are the local provisions for care overnight and at weekends?

*Below, you'll find a few propositions that **could** help stimulate the discussion as well (these*

propositions contain elements that are available for probing. E.g., the ‘how-question’):

1. Please respond: “Well integrated palliative care facilitates open communication about death and dying based on patients and family needs.”
2. Please respond: “Well integrated palliative care contains evaluation of pain and other physical and psychological symptoms with adequate access to medications and equipment.”
3. Please respond: “Well integrated palliative care contains multidisciplinary care services at generalist and specialist level to provide high quality care at any time during day or night, based on the patient’s condition, care plan and wishes.”
4. Please respond: “Well integrated palliative care attends to the support needs of bereaved carers”.

Step 4: Description of the integrated palliative care initiative – availability of materials and personnel

1. How does ‘the initiative’ ensure that people with expert knowledge are available to supply the right medication/equipment at the right time?
2. How is the provision of drugs – particularly pain relief and drugs for use at end of life – organised and who takes responsibility for this? **(issues about medication that are raised in the patient/carer interviews)**
3. How is the provision of ADL aids and other equipment organised and who takes responsibility for this?

In addition to the questions/propositions: you could prepare yourself by reading through the interview material and use some striking elements concerning [e.g., patient logistics] to challenge/compliment participants and to further stimulate discussion. If the interview is chaired by another person than the researcher, you’ll have to provide the chair beforehand with these ‘striking elements’.

Closure

* Thank the participants for partaking in this focus group. Explain them what will happen from here on with the research material and when and how they will be able to read anything about the research project. If suitable in your country, hand over to the participants the small present for participation and inform them about reimbursement of travel expenses.

Refreshments

Suggestion: read the information below for additional information on what to expect. Some elements could help you to build probing questions or pick critical elements from the interviews. This information also gives you a first insight into the elements we will be looking for in the analysis.

- **Delivery system integration:** the extent at which at the macro level of the care system financing and regulation are aligned for palliative care within and between cure, care and social services. Hindering and stimulating factors at this level can be identified for example:
 - Information logistic may be problematic if regulations do not allow to share patient information across hospital and social care.
 - Integration may be stimulated if cure, care and social services are allowed to transfer and share resources.
- **Functional integration:** The extent at which at the meso level support activities (finance, management and information systems) and organizational structures are aligned for palliative care within and between cure, care and social services.
What are the structures they introduced at this level or what are the hindering factors; for example:
 - sharing administration to avoid duplication of activities.
 - Introducing an electronic medical record across settings
 - Building an organisation that works across cure, care and social care.
- **Clinical integration:** The extent at which at the micro level care delivery activities are aligned between care givers for palliative care within and between cure, care and social services. What has helped integration at this level and what are hindrances;
 - sharing patient information; formal (paper; electronic patient files?) & informal (telephone/ teleconsultation/e-mail)
 - multidisciplinary team meetings for decision making (*let participants explain the choices that have been made; let them explain the (potential) value of multidisciplinary team meetings*)
 - patient/family caregiver-inclusive team meetings for decision making (ibid.)
 - collaborative interventions at a patient's bedside (ibid.)
 - *protocols/pathways*
 - (therapeutic) continuity for the patient
 - attuned care for the patient
 - collaboration with the patient/family caregiver

- **Cultural integration:** The extent at which norms, values and approaches of care givers are aligned.
What helped them align norms and values or where do they experience problems.
 - training activities and evaluations; within and between disciplines/institutions (ibid.)
 - a shared philosophy on paper; a signed mission statement. (What did your initiative do to co-create such a philosophy?)
 - collaboration towards a shared philosophy in practice. (What has been done to implement the philosophy into daily practice? How did that work out?)
- **Social integration:** The extent at which social relations between caregivers are intensified; trust.
What did they do to intensify relationships and trust, where do they experience problems?
 - visits; internships, meetings.
 - concrete definitions of the different responsibilities and roles of the various professionals/ volunteers/patients/family caregivers
 - versatile and flexible professionals who can build on each other
- **Strategic integration:** The extent at which goals, means, power and interests of organizations and caregivers are aligned.
What did they do to align goals, means, power and interests. Where do they experience problems?
 - Hired an independent project coordinator
 - Used a specific implementation strategy.

